

**BUILDING A STRONGER PARTNERSHIP:**

**TECHNICAL ASSISTANCE CONFERENCE CALL FOR  
TITLE I PLANNING COUNCILS TITLE II CONSORTIA, AND THE  
NATIONAL AIDS EDUCATION AND TRAINING CENTERS (AETC)  
PROGRAM**

Held March 16, 1995

Arranged by :  
Division of HIV Services  
Bureau of Health Resources Development  
Health Resources and Services Administration  
U.S. Department of Health and Human Services

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## EXECUTIVE SUMMARY

This report summarizes the information presented in “Building a Stronger **Partnership,**” the fifth in a series of national technical assistance teleconference calls arranged by the Division of HIV Services (DHS) as a means of providing information and ideas to the Ryan White CARE Act network, particularly Title I planning councils and Title II consortia.

The purpose of the teleconference was to explore activities related to strengthening partnerships between Ryan White CARE Act Title I and II grantees, planning councils, HIV care consortia, and projects supported by the AIDS Education and Training Centers (AETC) Program. HRSA believes that collaborative partnerships can help meet the training needs of local health care providers and ultimately the service needs of people living with HIV/AIDS. The conference call was broadcast by DHS on March 16, 1995, from the semi-annual meeting of the National AIDS Education and Training Center (AETC) Program Directors. Panelists and guest speakers discussed specific examples of collaborative partnerships as well as addressing other specific training issues.

The teleconference included an update on Ryan White CARE Act reauthorization. Bipartisan support for reauthorization was demonstrated at a recent hearing in the Senate. A number of issues remain to be resolved, including formula funding for Ryan White CARE Act Titles I and II and funding limits on administrative expenditures. Language authorizing the National AETC Program may be moved from the Public Health Service Act into the CARE Act.

The teleconference presented varied examples of collaborative partnerships between AETCs and Title I and Title II grantees, planning councils, and HIV care consortia, as well as ways in which the AETCs are addressing training issues important to the CARE network. The information presented shows that the AETC Program is providing a range of training and related services with impact upon CARE Act programs. Models exist for many types of AETC collaboration with various segments of the Ryan White network, including activities designed to meet a variety of specific training needs -- such as training for minority providers, training in rural and remote areas, and case manager training. The type and extent of collaboration varies greatly. The information provided during the teleconference may suggest potential areas for new partnerships.

HRSA believes that collaboration and partnerships between AETCs, CARE Act grantees, planning councils and consortia, and other segments of the Ryan White network, will help to meet the training needs of providers and the service needs of persons living with HIV/AIDS. Ultimately, this will improve the quality and accessibility of treatment services to people with HIV/AIDS throughout the country.

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# **I. INTRODUCTION**

## **A. BACKGROUND AND PURPOSE**

This report summarizes the information presented in "Building a Stronger Partnership," the fifth in a series of nationally broadcast technical assistance telephone conference (teleconference) calls arranged by the Division of HIV Services (DHS), Health Resources and Services Administration (HRSA). The conference call was broadcast by DHS on March 16, 1995, from the semi-annual meeting of the National AIDS Education and Training Center (AETC) Program Directors.

The purpose of the teleconference was to explore activities related to strengthening partnerships between Ryan White CARE Act Title I and II grantees, planning councils, HIV care consortia, and projects supported by the AIDS Education and Training Centers (AETC) Program. HRSA believes that collaborative partnerships can help meet the training needs of local health care providers and ultimately the service needs of people living with HIV/AIDS,

The hour-long teleconference included panelists from the DHS and guest speakers from AETCs and the Ryan White CARE Act network, as well as callers with questions related to the agenda. (See Appendix A for a list of panelists and guest speakers.)

## **B. PROCESS**

Like the other teleconference calls in this series, this call reflected careful planning to determine topics to be covered, as well as opportunities for listeners to raise questions during the call. A letter was sent out in early February to AETC directors, Title I planning council Chairs, and Title I and II grantees, asking for questions related to collaborative partnerships involving the AETC and the CARE Act network. Based on the questions received, the panelists grouped questions into similar topic areas for discussion. (Appendix B contains the agenda that guided the teleconference call.) Registered callers received the questions prior to the call.

Seventy-five sites around the country participated in the call, including over 500 participants. All sites received evaluation forms; evaluations were received from 22 call participants.

Unfortunately, there were some technical difficulties with the calls, so that portions of speaker comments were inaudible. This report summarizes the available information, which is presented by topic rather than chronology

## **II. THE NATIONAL AIDS EDUCATION AND TRAINING CENTER PROGRAM**

### **A. PROGRAM OVERVIEW**

The National AETC Program began in 1987 with four projects that focused on educating health care professionals about the epidemiology of AIDS and HIV risk assessment. In response to the epidemic, the program had grown to 17 regional centers with over 75 local performance sites by 1991.

The **AETCs** are responsible for designated geographic areas where they conduct targeted multidisciplinary programs for health care professionals. The program now covers all 50 states, the Virgin Islands, and Puerto Rico -- with less than 2.5% of the total HRSA AIDS budget. Eleven programs are regional multi-state centers, and the other six are local or statewide.

The AETC Program now focuses on clinical training of primary care providers: physicians, nurses, dentists, nurse practitioners, physician assistants, and dental hygienists. Another important emphasis is mental health and allied health providers.

AETC Program goals are to:

- To provide training to increase the competence and willingness of health care professionals to diagnose, treat and manage HIV infection;
- To offer interventions that will prevent HIV infection; and
- To develop HIV service provider educational materials and disseminate state-of-the-art HIV information to providers.

### **B. ACCOMPLISHMENTS**

AETC Program accomplishments include the following:

- The AETC Program has trained more than 400,000 providers, including more than 110,000 in 1994 alone.
- The program has developed a comprehensive **data** collection system and ongoing formal evaluation activities.
- The program provides technical consultation to health care providers; it originated both of the following sources of up-to-date information:

- ◆ The toll-free HRSA HIV/AIDS ETC National Telephone Consultation Service at San Francisco General Hospital (800-933-3413); and
- ◆ The State-of-the-Art HIV Clinical Conference Call series

## C. PLANS

Future program training priorities include emphases on prevention, tuberculosis, and substance abuse. Each AETC will have a Ryan White CARE Act emphasis that includes:

- Containing at least one Title I **EMA**;
- Conducting needs assessments linked to the development of information dissemination; and
- Developing training plans specifically for CARE Act programs in all titles, with the dimensions of Ryan White emphasis dependent upon legislative alignment with Title XXVI.

## III. RYAN WHITE CARE ACT REAUTHORIZATION UPDATE

### A. STATUS

The teleconference call provided an update of recent activities regarding Ryan White CARE Act reauthorization.

The Senate Committee on Labor and Human Resources convened a hearing on the Act on February 22, 1995. Testimony was given by consumers, providers, national experts, and Dr. Philip Lee, Assistant Secretary of Health and Human Services. The General Accounting **Office** also provided testimony on funding formula issues. The hearing was perceived as a positive, bipartisan effort, with much support for the CARE Act expressed by committee members. The consensus from the hearing was that the CARE Act is working.

Congress has been using the **Kennedy-Waxman** bill from the last Congressional session as a basis for Senate Committee deliberations. If the committees in both houses take swift action, the reauthorization bill could be acted upon by Congress in the fall.

Sensitive issues that remain to be resolved include the establishment of funding formulas for Ryan White CARE Act Titles I and II, and funding caps for administrative expenditures.

## **B. THE AETC PROGRAM AND THE CARE ACT**

One issue under discussion is whether the AETC Program may become a separate title under the Ryan White CARE Act. The AETC Program is currently authorized under Title VII of the Public Health Service Act. This legislative location does not accurately reflect current linkages between the AETCs and Ryan White Program. A plan to move the AETC Program so that it is a part of the Ryan White CARE Act has the support of the HRSA Administrator, the Associate Administrator for AIDS, and the Department, as noted in the Assistant Secretary's Senate committee testimony. The move would maximize existing linkages and visibly demonstrate the role of the AETC Program within the national Ryan White CARE Act network.

## **IV. COLLABORATIVE PARTNERSHIPS**

### **A. COLLABORATION WITH PLANNING COUNCILS AND CONSORTIA**

#### **1. SUCCESSES**

The teleconference cited several successful examples of partnerships between Title I planning councils and Title II consortia and various AETC Programs. For example:

- The Western **AETC** in the Central Valley of California (Fresno) collaborates with the Central San Joaquin HIV Care (Title II) Consortium in supporting adult and pediatric HIV clinical care. The AETC targets training resources toward multidisciplinary team members in conjunction with service dollars from the consortium. Since AETC funds can be used only for provider education, Title II funds have been used to fund the service or "fellowship" component of the training experience. This partnership has expanded the quality of HIV care in the Central Valley of California.
- The Kansas **AETC** uses Title II dollars to support provider training in **all** four quadrants of the state. AETC resources provide the educational component -- including hands-on training. Title II resources provide a service component. Through the use of both AETC and Title II resources, in addition to clinic support from Ryan White CARE Act Title IIIb program, the state's needs are being addressed in a cost-effective manner.
- The New Jersey Title II consortia have successful linkages at several levels within the state. AETCs work with the nine Title II consortia to develop the regions' needs assessment process. The consortium coordinators **meet** on a monthly basis to get annual program and information updates from the AETC Program. The AETC and the Title II consortia have collaborated on two



statewide conferences that address specific Ryan White CARE Act issues related to all four titles of the Act. The conferences have evolved from an initial information-sharing format to skills-building and technical assistance activities.

- The HIV Professional Development Project in New York represents a successful collaboration, involving the Title I program, the New York AIDS Institute, the State Health Department, external consultants, and the AETC Program. The project holds professional support group meetings for providers to help alleviate the stresses of HIV care responsibility. The group meetings are conducted by mental health professionals and evaluated by a consultant. This project is also involved in the creation of model criteria and HIV practice experiences to be implemented in health professions schools. A monograph on critical practices used in HIV care that affect the recruitment and retention of professional staff is being developed for HIV care providers.

## 2. CHALLENGES

Speakers and panelists addressed two examples of challenges to successful collaboration and partnerships:

- Lack of **AETC** representation on planning councils or consortia. The Midwest AETC (MATEC) described its involvement with the Planning Council of Chicago. MATEC had been involved with AIDS planning for the Chicago area from the beginning of its AETC activities. Initially, however, the AETC was only a welcome observer, without a formal vote on the planning council. By inviting the planning council Co-Chair to become a Co-Principal Investigator on the AETC program, the AETC in effect received voting status. This arrangement facilitates ongoing program integration and collaboration. DHS internal policies encourage AETC representation on planning councils and consortia. While such representation is not currently a legislative requirement, reauthorization language may change this. AETC involvement may also occur in the working groups or subcommittees of the CARE Act planning bodies, where participants may not be formal council/consortium members.
- Concerns that planning council or consortium training needs are not being met. Another issues involves cases where a planning council or consortia believes their training needs are not being met. It was noted that the training needs of a planning council or consortium's membership may not necessarily overlap with AETC program priorities or its legislative mandate. In such situations, training needs are better handled through the DHS national technical assistance contract and DHS project officers.

### 3. INCREASING INFORMATION EXCHANGE

Suggestions were provided for increasing information exchange between the AETC program and the planning councils or consortia. The best way is to have everyone "at the table" during the planning process. All AETCs are required to collaborate with Title I and II grantees, and receive lists of grantees to facilitate this process. (See Appendix C for a list of Title I and Title II grantees and contacts.)

Title I and II grantees are not currently required to collaborate with the AETCs. However, DHS strongly encourages such collaboration through administrative means. DHS will be distributing *CARE Notes*, a Title I and II newsletter, to the AETCs and their performance sites. On the federal level, collaborations include joint staff meetings between DHS and AETC staffs, and collaborative technical assistance activities. Joint site visits on the local or state level are being considered.

#### **B. COLLABORATION WITH STATE HEALTH AGENCIES**

Several models for collaboration between state health agencies and AETCs were presented. While not all state health agencies have been involved with their AETCs, those with a history of such involvement have found it valuable.

- Michigan and the East Central **AETC**: Michigan's Chief of HIV/AIDS Prevention and Coordinator of CARE Act Programs is a faculty member of the East Central AETC in Columbus, Ohio. Michigan CARE Act sites have collaborated on conferences, planning, and needs assessment activities. In addition to federal encouragement and requirements, federal resources are required to foster these partnerships.
- The Delta AETC and Louisiana: The Delta AETC program in New Orleans has had a long-standing partnership with the state health agencies in its service area. The Delta AETC has been involved with statewide planning in Louisiana "from the beginning." Its activities have been conducted with the AETC taking the lead in provider training and state Title II dollars targeting prevention and education in the community. The collaboration has yielded a "State Initiative" which contributes substantial funding to provide training to health care providers in hospitals, early intervention sites, and ambulatory care sites around the state.

The Delta AETC is also collaborating with the Office of Public Health and the School of Pharmacy at Xavier University, an historically Black university on an effort targeting pharmacists throughout the state for HIV/AIDS education.

The AETC also works with the Office of Mental Health and the Office of Alcohol and Drug Abuse in Louisiana.

### **C. EVALUATING PARTNERSHIPS**

Evaluation must be built into the beginning of all collaborative partnership efforts. The evaluation must include needs assessment, measures of quality of care, and measures of patient outcomes. Technical assistance from either the state or HRSA is integral to the evaluation process.

## **V. TRAINING ISSUES**

Panelists, speakers, and callers explored a range of training and technical assistance issues which help to clarify AETC roles, programs, and limitations.

### **A. TECHNICAL ASSISTANCE**

The role and limits of the AETC Program as a technical assistance provider to community-based organizations was discussed.

The AETC Program provides technical assistance as it relates to training of health care providers and the development of health care systems. This assistance take two major forms:

- Training activities based on AETC-assisted needs assessments; and
- Information dissemination -- including printed newsletters, audio and video materials, electronic communication, the HIV clinical conference call series, and HRSA's HIV/AIDS ETC National Telephone Consultation Service. In April and May 1995, the program will feature satellite teleconference broadcasts on clinical issues for providers who care for persons in correctional facilities.

Grantees which wish to request technical assistance for community-based organizations which are their service providers can do so through the DHS Technical Assistance Contract with John Snow, Inc. This contract emphasizes peer-based interaction, with specialists from one state or EMA providing assistance to other states and EMAs. Consultants with many different specialties are available. To access this assistance, grantees should contact their DHS project officers.

## **B. PARTICIPATION OF PEOPLE LIVING WITH AIDS**

AETCs have had varied success in securing participation by people living with HIV/AIDS in the planning, implementation and evaluation of training programs. While certain AETCs have been very successful in including people living with AIDS in training programs, there is room for expanding this effort in other sites. Inclusion of PLWAs helps create opportunities to increase health care professionals' understanding of the barriers to care that patients experience.

Involving PLWAs as trainers and in other roles requires strategic outreach efforts to find people who have clinical or more technical experience. Local speakers bureaus, clinical trial research initiatives, electronic bulletin boards (e.g., Aegis), and the AIDS Clinical Trial Information Services all can help AETCs find potential trainers who are PLWAs. Increasing participation by PLWAs requires focused programming, such as a train-the-trainer format. The AETC Program appears well positioned for this role.

The AETC Program is actively committed to incorporating input from PLWAs in its program advisory, planning, training, implementation and evaluation efforts. All AETC centers have been reviewed for PLWA participation. All work actively with PLWAs in some capacity. Later this year, the National AETC Program will convene a major meeting of people living with HIV/AIDS to develop specific recommendations for increasing their involvement with the AETC Program.

## **C. TRAINING FOR MINORITY PROVIDERS**

An important issue in some states, and in Puerto Rico and the Virgin Islands, is the availability of training to address the needs of minority providers, particularly those with language barriers. The AETC in San Juan, Puerto Rico, provides training for Spanish-speaking providers.

It was suggested that certain inner-city communities, such as South Central Los Angeles, have a pressing need for provider training. Consumer participation on AETC advisory boards was suggested as a way to assist centers in the task of educating providers in community settings.

## **D. TRAINING IN RURAL AND REMOTE AREAS**

There are numerous difficulties associated with rural training with limited resources, among them episodic interventions at remote sites. The AETCs have several initiatives designed to assist health care providers in rural areas:

- Telephone consultation: The HRSA/HIV/AIDS ETC National Telephone Consultation Service at San Francisco General Hospital has served as a key

support for rural training efforts. Many other AETCs have formal and informal clinical consultation services.

- Training key providers: The Western AIDS ETC has a “Key Provider Program” which is similar to the Clinical Scholars Program in New York. Recent training graduates (physicians, nurses, pharmacists, physician assistants) are enrolled in a longitudinal training effort that has built capacity in both urban and rural areas. It has been very successful in that most program participants have evolved into HIV leaders in their respective communities, able to educate other providers.
- Collaborative training: The Emory AIDS Training Network in Atlanta runs a project in rural Georgia. The need is much greater than the resources available. With the epidemic raging in the rural South, the Network has collaborated with the Region IV Public Health Service (PHS) to produce a conference directed at primary health care providers who practice at PHS-funded clinics and community health centers in the rural Southeast. A collaboration with the Title I grantee in Atlanta, Grady Health System, enables the AETC to provide hands-on clinical training for rural providers. In concert with the Title IV program in Atlanta, pediatric clinicians from all 17 Title II sites have been trained as well as providers from contiguous states. Strong linkages with state health agencies have allowed the AETC to collaborate on provider training.

#### E. CASE MANAGER TRAINING

Case managers have ongoing training needs. Some AETC centers train case managers, and Title I and Title II grantees also provide such training. AETC training costs may be prohibitive for some local Title II-funded agencies, especially where travel expenses are involved. Several examples were provided:

- The New Jersey AETC has helped to train over 800 Title I and II case managers during the past three years. The majority of training sessions were in the Newark EMA, and the AETC is now reaching out to other areas of the state. Based on needs assessments with case managers, a series of seven day-long training seminars have focused on issues such as gay/lesbian health care issues and networking in the community. Because this year’s needs assessment of Title II consortia revealed a need for similar training, the prior work will be replicated for the consortium network.
- The Chicago Department of Health provides Title I training for case managers. In order to not duplicate efforts, the training is conducted by the agency funded by Title I for case management. Experts in many fields are brought in to meet with the case managers centrally. A coalition of PLWAs

provides input regarding the adequacy of their HIV case management services. As the project expands to more rural sites, trained case managers serve as mentors to the new case managers.

## **F. PREVENTION-RELATED TRAINING**

AETCs provide training on HIV/AIDS prevention as well as treatment. For example, the Pennsylvania AETC carries out several prevention training efforts. After conducting a rigorous assessment of training needs in the area of prevention, the AETC has incorporated prevention components into its more intensive skill-building and hands-on clinical training programs.

- In collaboration with the Centers for Disease Control and Prevention (CDC), Pennsylvania AETC staff members became core trainers for **the** prevention counseling program. This program was then replicated across the state. They also assisted in the CDC-mandated prevention planning process, through both technical assistance and actual membership on the planning committee.
- The Pennsylvania AETC has been training with the Pennsylvania state correctional system since 1990, with prevention as a key training component. This activity capitalizes on a collaboration with the Office of the Governor. The AETC is currently developing a peer education program for the Department of Corrections, with inmate involvement.

## **V. CONCLUSIONS**

### **A. CONCLUSIONS**

The information presented during the teleconference call shows that the AETC Program is providing a range of training and related services with impact upon CARE Act programs. Models exist for many types of AETC collaboration with Title I and Title II grantees and other segments of the Ryan White network, including activities designed to meet a variety of specific training needs -- such as training for minority providers, training in rural and remote areas, and case manager training. The type and extent of collaboration varies greatly. The information provided during the teleconference may suggest potential areas for new partnerships.

HRSA believes that collaboration and partnerships between AETCs, CARE Act grantees, planning councils and consortia, and other segments of the Ryan White network, will help to meet the training needs of providers and the service needs of persons living with

HIV/AIDS. Ultimately, this will improve the quality and accessibility of treatment services to people with HIV/AIDS throughout the country.

## B. TELECONFERENCE EVALUATIONS

Twenty-two participants in the teleconference call provided written evaluations. In general, respondents found the call to be a useful forum for discussing examples of collaboration. Many respondents asked for written follow-up material, including a transcript or summary of the session, lists of AETC training programs and contact information, updates on the reauthorization, and information on specific topics such as rural case management. (A list of AETC programs with contact information is provided in Appendix D; the programs are further described in a journal article from *Public Health Reports*, found in Appendix E.)

Other substantive comments included the following:

- DHS should provide a “mandate” for a follow-up debriefing meeting between local or regional planning councils, consortia, and the appropriate AETC.
- Seeking partners is a two-way street, requiring effort from both the AETCs and the Ryan White network.

Suggestions were also made for improving the teleconference calls. Many participants felt the need for more question and discussion time. One participant recommended development of a glossary of common terms for distribution to participating sites. Almost all the evaluations commented on the audio problems that did not allow all speakers’ comments to be heard. The length of the call was also discussed; a few respondents found call too lengthy, or were not informed about its expected duration. In the future, a new audio system will be used and the calls will be only one hour.

### For More Information:

For more information on collaborative partnerships, contact any of the following:

National **AETC** Program Office:  
(301) 443-6364

Division of HIV Services:  
(301) 443-9091

Western AIDS Education and  
Training Center:  
(209) 252-2851

## **APPENDICES**



## APPENDIX A

### PANELIST AND GUEST SPEAKERS LIST

#### PANELISTS

Jon Nelson, M.S., Chief, Planning and Technical Assistance Branch, DHS  
Steven Young, M.S.P.H., Chief, Eastern Services Branch and Acting Chief, Western Services Branch  
Elaine M. **Daniels**, M.D., Ph.D., Director, National AIDS Education and Training Centers (AETC)  
E. Michael **Reyes**, M.D., M.P.H., Project Director, Western AIDS ETC and Ryan White Title I/II Liaison to AETC Program

#### GUEST SPEAKERS

Pat Nisler, Representative of the New Jersey State Department of Health, Title II Consortium  
Nathan Linsk, Ph.D., Principal Investigator, Midwest AETC  
Randy Pope, Chief of HIV/AIDS Prevention for the State of Michigan  
Bill **Brandon**, M.D., M.P.H., Medical Consultant to the AETC Program  
Stacy Vogan, M.P.H., Project Coordinator, Delta Region of the AETC in New Orleans  
Bill Lotterro, Massachusetts Department of Public Health and PLWA Training Consultant  
Debra **Bartelli**, M.P.H., Co-Principal Investigator, New Jersey AETC  
Judith Johns, Associate Commissioner for Health, Chicago Department of Health  
Linda Frank, M.S.N., Ph.D. R.N., Co-Principal Investigator, Pennsylvania AETC  
Ira Schwartz, M.D., Principal Investigator, Emory AIDS Training Network, Atlanta

**TA Conference Call**  
**Title I Planning Councils, Title II Consortia and National AIDS**  
**Education and Training Centers (AETC) Program:**  
**Building a Stronger Partnership**  
**March 16, 1995**  
**2:00 P.M. (EST)**

**Purpose:** The purpose of this teleconference is to explore activities related to strengthening partnerships between Titles I and II grantees, planning councils, consortia, and the AETCs. These partnerships will focus on meeting the local health care provider training needs and the needs of persons living with HIV.

**Panelists:** Steven Young, M.S.P.H., Chief Eastern Services Branch/Acting Chief Western Services Branch; Elaine M. Daniels, M.D., Ph.D., Director, National AIDS Education and Training Centers Program; Michael Reyes, M. D., M.P. H, Liaison to the AETCs; and Title I, Title II, and AETC representatives to be named.

**Topics and Questions:**

I. Welcome and Introductions

II. Program Update

"What are HRSA's expectations for programmatic collaboration between Titles I and II grantees and the AETC program?"

"What is the local flexibility for CARE and AETC grantees to meet their training needs?"

III. CARE Act Reauthorization Update

"What is the status of the reauthorization of the CARE act?"

"Will the AETC program become a separate title under the reauthorized CARE act?"

IV. Collaboration Issues (Successes and Challenges)

"What are some examples of planning councils and consortia working with AETCs?"

"What happens ~~when~~ an AETC cannot ~~secure~~ a position on a Planning Council or Consortium?"

"What happens when a Planning Council or Consortium believes that their training needs are not being met?"

"How do we get more information about the AETC program to the Planning Councils/Consortia (and vice versa)?"

"How do the AETCs collaborate with State Health Agencies?"

"How do you secure PLW-HIV/AIDS participation in the planning, implementation, and evaluation of training programs?"

"How do you secure technical assistance for CRO's - particularly in remote areas?"

V. Training Issues

"How do you meet training needs in rural areas and urban areas?"

"How do you meet the training needs of case managers?"

"Do the programs have a role that relates to the training issues of housing?"

"Buddy system recruitment?" Alternative therapies?"

"How do we meet our prevention-related training needs?"

VI. Next steps

"How will these collaborations between partners Planning Council, Consortia, and AETC programs be evaluated?"

VII. Closing Statements

Ryan White CARE Act Title I **EMA** Contacts

City	Contact Person	Planning Council Chairperson
<b>Atlanta/Fulton County</b>	<p><b>Mitch J. Skandalakis</b> Chairman Board of Commissioners of <b>Fulton County</b> County Government Center 141 <b>Pryor</b> Street, 10th Floor Atlanta, GA 30303 404 730-8204 FAX 404 730-4754</p> <p>Kathy Bush Ryan White Projects Epidemiology and Prevention Branch 2 Peachtree Street, N.W. 10th Floor, Room 400 Atlanta, GA 30303-3186 404 657-3129, FAX 404 657-3119</p>	<p>James F. Martin Georgia State Representative 44 Broad Street, Suite 500 Atlanta, GA 30303 <b>404 522-0400</b> FAX 404 657-82;</p>
Austin	<p>Pat Feagin Program Coordinator HIV/CAP Austin/Travis County Health Department 327 Congress, Suite 500 Austin, TX 78701 512 476-1349 FAX 512 472-6409</p>	<p>Tom Sheffield 2512 Exposition Blvd. Austin, TX 78703-1715 5 12 478-2950 FAX 512 708-1917</p>
Baltimore	<p><b>Arista Games, M.D.</b> Assistant Commissioner Preventive Medicine and Epidemiology Baltimore City Health Department 303 East Fayette Street, 5th Floor Baltimore, MD 21202 410 396-4438 FAX 410 625-0688</p>	<p>John G. Bartlett, (Co-Chair) Blalock 1111 600 North Wolfe Street Baltimore, MD 21205 410 955-3150 FAX 410 955-</p> <p>Carl Stokes (Co-Chair) Room 516, City Hall 100 North Holliday Street Baltimore, MD 21202 410 <b>396-4810</b> FAX 410 539-c</p>
Bergen/Passaic	<p><b>Catherine Correa</b> Project Director/Ryan White City of Paterson Department of Human Resources 125 <b>Ellison</b> Street, 1st Floor Paterson, NJ 07505 201 881-3394 FAX 201 278-3973</p>	<p>Karen Walker Paterson Counseling Center 319 Main Street Paterson, NJ 07505 202 523-83 16 FAX 201 523-5116</p>

City	Contact Person	Planning Council Chairperson
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### Educating Primary Care Providers About HIV Disease: Multidisciplinary Interactive Mechanisms

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#### Synopsis .....

*As HIV-related prophylactic and therapeutic research findings continue to evolve, the Health Resources and Services Administration (HRSA) of the Public Health Service has created multidisciplinary mechanisms to disseminate new treatment options and educate primary care providers at rural and urban sites throughout our nation's health care system.*

*HRSA has implemented (a) the International State-of-the-Art HIV Clinical Conference Call Series, (b) the national network of AIDS Education and Training Centers, (c) the nationwide HIV Telephone Consultation Service, and (d) the Clinical Issues Subcommittee of the HRSA AIDS Advisory Committee.*

*These collaborative and comprehensive efforts at HIV information dissemination target physicians, nurses, physician assistants, dentists, clinical pharmacists, mental health care providers, case managers, and allied health professionals. The sites where they provide care include public health clinics; county, State and Federal correctional facilities; private practice offices; community and academic hospitals, military and Veterans Administration facilities, hemophilia centers; schools of medicine, nursing, and dentistry; departments of health; chronic care facilities; visiting nurse and home care agencies; health maintenance organizations; and Indian Health Service clinics and hospitals.*

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IN THE UNITED STATES, more than 100,000 persons are living with AIDS, and as many as a million are believed to have HIV infection. The nation's need for HIV knowledgeable and skilled primary care providers continues to grow as the number of infected persons and length of survival increase.

If management of HIV infection and AIDS is limited to tertiary specialty settings, many infected patients will not receive the benefit of new knowledge about this chronic and progressive disease. Primary care providers who feel inadequately prepared in the face of rapid research developments may be reluctant to include people with HIV infection or

AIDS in their clinical practice. In addition, quality care for people with HIV infection and AIDS often requires that the provider address issues not traditionally well covered in the education of health professionals, such as sexuality and addictive disease.

Therefore, the Health Resources and Services Administration (HRSA) of the Public Health Service has implemented specific programs that are dedicated to the education and training of primary care providers in clinical management of HIV Infection and AIDS and that facilitate the timely dissemination of new HIV related treatment information as it becomes available. HRSA sponsors the International State-of-the-Art HIV Clinical Conference Call Series, the national network of AIDS Education and Training Centers, the nationwide HIV Telephone Consultation Service, and the Clinical Issues Subcommittee of the HRSA AIDS Advisory Committee (1-3).

#### International Clinical Conference Calls

The HIV Clinical Conference Call Series is a collaborative venture between HRSA, the National Institute of Allergy and Infectious Diseases (NIAID) of the National Institutes of Health, the Centers for Disease Control and Prevention, and expert clinicians and educators from academia. During these live multidisciplinary interactive audio teleconferences, primary care providers and educators have the unique opportunity to sequentially address timely clinical issues with internationally renowned clinical experts. New telephonic bridging technologies, such as electronic polling, allow participating sites to interact with experts in a highly organized and cost-effective manner. Providers can obtain printed transcriptions of the teleconferences, thus maximizing access to the programs' state-of-the-art information.

Established in September 1992, the quarterly HIV clinical conference calls have expanded to involve thousands of participants at hundreds of urban and rural clinical sites throughout the contiguous United States and in Alaska, Hawaii, Puerto Rico, St. Croix, and St. Thomas.; Clinical sites range from large medical centers to public health clinics, to individual practitioners' private practice offices. Each state-of-the-art program is accredited for category I continuing education for participating physicians, physician assistants, and nurses through collaborative arrangements with Linda Frank, PhD, and Monto Ho, MD, at the University of Pittsburgh Graduate School of Public Health, and Wilma Morgan, RN, at the Indian Health Service Clinical Support Center in Arizona.

Two-phase pre-program needs assessments are performed prior to each session, using facsimiles as

the primary communication modality. During phase 1 of each needs assessment, clinically relevant topics are solicited from the participating primary care providers and educators (for example, the topic "Prophylaxis: Prevention of Opportunistic Infections" was chosen for the February 1994 session).

During phase 2, participants submit specific questions regarding the chosen topic, such as "Is there a role for atovaquone in *Pneumocystis carinii* prophylaxis?" The questions are then collated into a final format, and an agenda is produced; it is distributed by facsimile to the participants and expert consultants before each clinical conference call. During the conference calls, the collated submitted questions, as well as additional "live-on-the-air" followup questions from listeners, are answered by expert clinicians.

Availability of the programs is promoted directly to HRSA and NIAID grantees, as well as through numerous collaborators—the National Association of Community Health Centers, National Hemophilia Foundation, Department of Veterans Affairs, Department of Defense, and State departments of health. Through the use of speaker phones, sites have as many as 77 participants using a single line, making the program cost effective. As a public service, the expert consultants participate in the conference calls from their offices; thus, there are no travel or honoraria expenses.

The first in this series of state-of-the-art HIV clinical conference calls occurred in September 1992. The topic selected by primary care providers and educators was tuberculosis and multidrug resistant disease. Arthur Pitchenik, MD, a pulmonary subspecialist caring for patients with HIV disease and multidrug resistant tuberculosis in Miami, FL, served as the expert consultant for the interactive 2-hour program.

The second clinical conference call was held in November 1992, and the topic selected was the use of ddI (dideoxyinosine) and ddC (dideoxycytidine). The expert consultants for this 1-hour session were Paul Volberding, MD, and Michael Clement, MD, at San Francisco General Hospital.

The third clinical conference call, held in February 1993, was devoted to therapeutic HIV vaccines. The expert consultants were Lewellys Barker, MD, of NIAID in Bethesda, MD, and David Chernoff, MD, at the Chiron Corporation in Emeryville, CA.

For the fourth clinical conference call, in April 1993, two topics were selected. The Idiopathic CD4 lymphocytopenia syndrome was discussed by Scott Holmberg, MD, at the Centers for Disease Control and Prevention in Atlanta, GA. The second topic,

convergent combination therapy with nonnucleoside reverse transcriptase inhibitors, was discussed by H. Clifford Lane, MD. and Dr. Barker, both of NIAID in Bethesda.

The fifth clinical conference call, in July 1993, was devoted to the clinical implications of the Anglo-French Concorde Trial of Zidovudine. The expert consultants were Dr. Volberding and Dr. Barker. As a followup, the sixth clinical conference call, in October 1993, discussed the spectrum of antiretroviral clinical management options. The expert panel of consultants included Gifford Leoung, MD, at San Francisco General Hospital; Renslow Sherer, MD, at Cook County Hospital in Chicago; Bruce Soloway, MD, at Bronx Lebanon Hospital in New York; and Eric Goosby, MD, at HRSA in Rockville, MD.

The seventh clinical conference call, in February 1994, was devoted to the spectrum of primary and secondary prophylactic regimens for the prevention of opportunistic infections. The panel of experts included Frederick Hecht, MD, at San Francisco General Hospital, Dr. Sherer, and, Dr. Goosby.

More than 2,500 primary care providers and educators at 377 sites participated in this session, including listeners at sites overseas. In collaboration with HRSA's Office of International Health and the U.S. Agency for International Development, we expanded the clinical conference call series to participating sites in Belize, Peru, Kuwait, Ghana, and the Republic of China (Taiwan). In collaboration with the U.S. Information Agency's Voice of America, portions of our clinical conference calls have been translated into Creole, Urdu, Thai, Russian, Rumanian, Spanish, and Portuguese; the Voice of America has broadcast segments of our conference calls worldwide in these seven languages and English.

Among the 377 registered sites, participants in our clinical conference calls include physicians, nurses, physician assistants, dentists, clinical pharmacists, mental health care providers, case managers, and educators. The sites include community and migrant health centers; public health clinics; providers of care to the homeless; substance abuse and sexually transmitted disease clinics; Indian Health Service clinics and hospitals; private practice offices; health maintenance organizations; community and academic hospitals; Veterans Administration Medical Centers; clinics and hospitals of the U.S. Air Force and Army; hemophilia centers; schools of medicine, nursing, and dentistry; departments of health; medical clinics at county, State, and Federal correctional facilities; visiting nurse and home care agencies; chronic care facilities; Area Health Education Centers; reference

*'Each clinical conference call session is followed by a post-program evaluation. Participants are asked to evaluate the presentations and to comment and suggest future topics. The 1-page forms are faxed back to HRSA.'*

specialists at the AIDS Clinical Trials Information Service; the American Medical Association's Division of HIV in Chicago; AIDS Education and Training Centers; and NIAID-supported Community Programs for Clinical Research on AIDS and AIDS Clinical Trials Units.

Each clinical conference call session is followed by a post-program evaluation. Participants are asked to evaluate the presentations and to comment and suggest future topics. The 1-page forms are faxed back to HRSA. Evaluations have revealed that the topics and expert consultants have been timely, relevant, and informative; conference rooms with speaker phones at clinical sites offer comfortable interactive settings for participating staff providers and educators; clinicians in private practice appreciate the opportunity to participate from their offices without having to travel to academic sites; and participants appreciate receiving the collated list of questions and the glossary of relevant terminology (for example, intention to treat analysis, meta analysis, Kaplan Meier survival curves, hazard ratio) in advance of each session.

To obtain further information and registration forms for the next International State-of-the-Art HIV Clinical Conference Call, send correspondence by FAX to Captain Abe M. Macher, MD, USPHS, at 301-443-1719.

## **AIDS Education and Training Centers**

Through cooperative agreements, a nationwide network of 17 AIDS Education and Training Centers are funded by the Health Professions HIV Education Branch, Division of Medicine, Bureau of Health Professions, HRSA. Since 1987, the AIDS Education and Training Centers have been responsible for designated geographic areas where they conduct targeted multidisciplinary programs for health care professionals. Eleven programs are regional multi-State centers, such as the Northwest AIDS Education and Training Center which serves Alaska, Washington, Oregon, Montana, and Idaho. Six centers are

## Program Directors and Areas Served by AIDS Education and Training Centers (ETC)

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**Oregon**

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Riverside, San Bernardino, Los Angeles, Orange, Ventura, Santa Barbara Counties, CA

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North Dakota, South Dakota, Utah, Colorado, New Mexico, Nebraska, Kansas, Wyoming

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Texas and Oklahoma

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**AIDS ETC for Texas and Oklahoma.** University of Texas. Houston

Illinois, Indiana, Iowa, Minnesota, Missouri, Wisconsin

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Ohio, Michigan, Kentucky, Tennessee

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Connecticut, Maine, **Massachusetts, New Hampshire, Rhode Island, Vermont**

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New York/the Virgin Islands

Cheryl Heaton, DrPH, 212-305-3616

**New York and Virgin Islands AIDS ETC.**

Columbia University School of Public Health. New York City

New Jersey

Gigi Diamond. MD, 201-982-3690

**New Jersey AIDS ETC.** University of Medicine and Dentistry of New Jersey. Newark

**Delaware,** Maryland, Virginia, West Virginia

Lisa Kaplowitz, MD, 804-371-2447

**Mid-Atlantic AIDS ETC.** Medical College of Virginia, Richmond

Metropolitan Washington DC area

Eric Moolchan. MD, 202-806-4002

**District of Columbia AIDS ETC.** Howard University, Washington, DC

Alabama, Georgia, North Carolina, South Carolina

Ira Schwartz. MD, 404-727-2929

**Emory AIDS Training Network.** Emory University, Atlanta, GA

Florida

Howard Anapol. MD, 305-585-7836

**Florida AIDS ETC.** University of Miami

Puerto Rico

Angel Bravo. MPH, 809-759-6528

**Puerto Rico AIDS ETC.** Univcnity of

Puerto Rico. Rio Piedras

local or statewide, such as those serving Pennsylvania, New Jersey, Florida, Puerto Rico, the District of Columbia, and the area surrounding Los Angeles (see box).

The AIDS Education and Training Centers provide both didactic and clinical training. Didactic mechanisms include lectures, grand rounds, seminars, symposia, workshops, local and regional teleconferences, and instructional audiotapes, videotapes, and

computer programs. The centers also offer intensive experiential "hands-on" clinical miniresidencies for allopathic and osteopathic physicians, nurses, nurse practitioners, physician assistants, dentists, and dental hygienists. The centers serve as resource centers; they offer local and regional clinical consultation warm-lines, provide referrals for clinical care, and supply information about available clinical trials and expanded availability of medications.

## HIV Telephone Consultation Service

The nationwide HIV Telephone Consultation Service is co-sponsored by HRSA's Western AIDS Education and Training Center, the American Academy of Family Physicians, HRSA's Bureau of Health Resources Development, and the Office of AIDS Research of the National Institutes of Health.

In March 1993, the regional HIV clinical consultation **warmline** at San Francisco General Hospital was expanded to serve the entire nation. Health care providers can call a toll-free number (1-800-933-3413) from 10:30 a.m. to 8 p.m. Eastern Time Monday through Friday, and expert consultants will answer their HIV-related clinical management questions (after hours, or if the line is busy, the caller can leave a recorded question, and a consultant will return the call). Dr. Ronald Goldschmidt of the Department of Family and Community Medicine, University of California at San Francisco, directs this multidisciplinary expert consulting team of four physicians, four clinical pharmacists, and two nurse practitioners. The clinical pharmacy consultants, directed by Kirsten Brossier Balano, PharmD, are a critical component of this service, as 47 percent of callers receive consultation from a clinical pharmacist.

Through February 1994, the **warmline** had received more than 4,100 calls and 4,600 questions. Questions spanned the spectrum of HIV disease including testing and counseling, evaluation of symptoms, developments in therapy, and drug-drug interactions. The consultation service averages 15 to 20 calls per day. Evaluation of caller data through November 1993 demonstrates that 41 percent of callers had used the consulting service more than once. Fifty-four percent of the callers were physicians, 21 percent were nurses, 7 percent were pharmacists, and 5 percent were nurse practitioners. The majority of the physicians, 50 percent, were in family practice, 23 percent in internal medicine, 5 percent in infectious diseases, and 3 percent in general practice. The callers' sites of practice were as follows: 22 percent a community clinic, 18 percent a private practice, 6 percent in home health care, 3 percent a health maintenance organization, and the remainder were from a variety of other clinical sites, including hospital-based inpatient and outpatient services.

## Clinical Issues Subcommittee

The Clinical Issues Subcommittee of the HRSA AIDS Advisory Committee was formed in 1993 to

## Members of the Multidisciplinary Clinical Issues Subcommittee of the HRSA AIDS Advisory Committee

Ann Williams, RN, EdD, Chairperson  
Yale School of Nursing

Joanne Allport, MD, MPH  
National Institutes of Health

Jean Anderson, MD  
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Kirsren Brossier-Balano, PharmD  
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Richard D'Aquila, MD  
Massachusetts General Hospital

Elaine Daniels, MD, PhD  
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Iris Davis, MD  
University of Maryland School of Medicine

Eric Goosby, MD  
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Wayne Greaves, MD  
Howard University Hospital

Samuel Grubman, MD  
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Pearl Katz, PhD  
Health Resources and Services Administration

Gifford Leoung, MD  
University of California at San Francisco

Abe Macher, MD  
Health Resources and Services Administration

Harvey Makadon, MD  
Beth Israel Hospital

Alvin Novick, MD  
Yale University

Patricia Randall  
National Institutes of Health

Jaime Rivera-Dueno, MD  
San Juan AIDS Institute

Bruce Soloway, MD  
Bronx Lebanon Family Practice Center

Jack Whitescarver, PhD  
National Institutes of Health

respond to the needs of primary care providers **on the front lines of HIV care who are sometimes uncertain about the** clinical implications of fast breaking, widely reported, but often quite specialized research findings. The subcommittee's task is to interpret such studies in the context of direct patient care and to provide guidance to HRSA regarding transmission of this new information to the many clinicians and clinical sites supported by HRSA, as well as to the larger community of clinicians through the nationwide network of AIDS Education and Training Centers.

The subcommittee does not write clinical guidelines, but the members rather work to provide clinicians in the community with support in understanding the practice implications of the results from research studies. For example, several subcommittee members collaborated on a "clinical commentary" that addressed the implications of convergent combination antiretroviral therapy for patients and primary care providers; the commentary appeared in April 1993, at a time when press coverage and activist demands had led to considerable confusion among patients. Copies of the clinical commentary, published in AIDS Clinical Care, were mailed to thousands of primary care providers through the nationwide network of AIDS Education and Training Centers (4).

The subcommittee is broadly multidisciplinary as it is composed of nurses, family practitioners, general internists, infectious disease subspecialists, 3 pediatrician, an obstetrician-gynecologist, a psychiatrist, an epidemiologist, 3 clinical pharmacist, and 3 clinical pathologist (see box, page 309). Members were recruited who had substantial experience in both HIV-related research and clinical care. Therefore, members of the clinical issues subcommittee also serve as expert panelists in our International State-of-the-Art HIV Clinical Conference Call Series. Members Gifford Leoung, MD, and Bruce Soloway, MD, served on the October 1993 panel that addressed the spectrum of antiretroviral treatment options.

The interface between basic research and clinical practice is of great importance across health care topics and disciplines; it is hoped that the subcommittee's approach to HIV infection will offer a model for addressing this challenge in a number of other medical arenas.

## Conclusion

During an era of rapidly changing HIV-related concepts and research findings, HRSA is generating and promoting multidisciplinary mechanisms to dis-

seminate new treatment options to primary care providers. Four successfully implemented efforts include the International State-of-the-Art HIV Clinical Conference Call Series, the national network of AIDS Education and Training Centers, the nationwide HIV Telephone Consultation Service, and the Clinical Issues Subcommittee.

## References .....

1. Macher, A. et al. The international state-of-the-art HIV clinical conference call series. In Proceedings of the Ninth International Conference on AIDS. Abstract PO-D14-3815, p. 853. Berlin, Germany. June 1993.
2. Macher, A. et al. The 17 multidisciplinary AIDS education and training centers of the United States Public Health Service. In Proceedings of the Ninth International Conference on AIDS. Abstract WS-D13-4, p. 116. Berlin, Germany. June 1993.
3. Macher, A. et al. HIV information dissemination to primary care providers. In Proceedings of the Ninth International Conference on AIDS. Abstract PO-D14-3816, p. 854. Berlin, Germany. June 1993.
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## **NEEDS ASSESSMENT**

### **TECHNICAL ASSISTANCE CONFERENCE CALL**

**HELD MARCH 26, 1996**

Arranged by:

Division of HIV Services  
Bureau of Health Resources Development  
Health Resources and Services Administration  
U.S. Department of Health and Human Services

Report Prepared by:

**MOSAICA**  
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June 1996

UNDER CONTRACT TO **JSI** JOHN SNOW, INC.

## EXECUTIVE SUMMARY

This report summarizes the information presented in "Needs Assessment for Titles I and II," the tenth in a series of nationally broadcast technical assistance telephone conference (teleconference) calls arranged by the Division of HIV Services (DHS), Health Resources and Services Administration (HRSA). The report reflects both the content of the presentations and the questions and comments from listeners during the call. The teleconference was broadcast March 26, 1996. More than 1,300 individuals from 220 different sites participated in the teleconference, making this the largest technical assistance conference call so far.

The purpose of the teleconference call was to discuss and clarify requirements and expectations related to needs assessment for Title I and Title II, and describe the needs assessment process itself. The call focused on current and pending legislative requirements and DHS expectations related to needs assessment, components of a needs assessment, a step-by-step process for needs assessment, factors to consider in conducting a needs assessment -- particularly involvement of the PLWH community -- and tools and methods used in needs assessment.

Needs assessment is the cornerstone of the Ryan White planning process. The CARE Act recognizes the role of needs assessment in developing an array of services for people living with HIV and AIDS, and requires Title I EMAs and Title II consortia to assess service needs. Under Title I, the needs assessment process is considered a partnership activity involving the grantee, the planning council, and the community. Title II consortia must demonstrate it has carried out an assessment of need, has developed a plan to meet those needs, including special care and service needs, and that this process has included the participation of individuals living with HIV disease.

The reauthorized Act is more prescriptive in its requirements for needs assessment. For example, under Title I there is more specificity with regard to the needs assessment process and documented need, in terms of both program requirements and funding. Title I grantees are required to participate in the Statewide Coordinated Statement of Need (SCSN) initiated by the agency administering Title II funds, and must demonstrate that services provided in the EMA are consistent with that Statement. Title I grantees must also establish methods for obtaining input on community needs and priorities, including such approaches as public meetings, focus groups, and *ad hoc* panels. Finally, the new legislation defines a measurement of severe need based on certain co-morbidity - such as sexually transmitted diseases (STDs), substance abuse, tuberculosis, severe mental illness, AIDS in previously unknown populations, and homelessness, where such data are available. This measurement will eventually be used to measure and compare severe need across EMAs. The new legislation further reinforces Title II requirements for needs assessment. Under Title II, services funded at the state level will be required to include a description of how allocation

and utilization of Title II funds are consistent with the SCSN, and require that it be developed in partnership with other CARE Act grantees.

DHS has certain expectations related to needs assessment. The needs assessment process is expected to be participatory and inclusive, involving broad representation from the community and people living with HIV (PLWH). Needs assessments should include quantitative as well as qualitative data, and should consider the needs of those in and out of care. The Title I and Title II application guidance provides further clarification on the needs assessment process.

The needs assessment sets the stage for the planning process by identifying the needs in the community, the services available to meet the needs, and the gaps between needs and services. However, the needs assessment can be a meaningless exercise if not planned carefully. The following steps are suggested as a logical approach to the needs assessment process: (1) determine the approach to be followed, (2) develop a timetable and budget, (3) establish a process for community input, (4) select the methods to be used, (5) design the data collection instrument(s), (6) collect all the information, and (7) determine the outcome.

Some basic factors to consider when conducting your needs assessment include: (1) who should conduct the assessment, (2) the length and frequency of the needs assessment process, (3) activities to keep information updated, and (4) who should be targeted in the assessment. Decide from the onset who will be responsible for conducting the needs assessment -- staff, consultant(s), or other individual(s) -- and assure buy-in from all participants. Ideally, needs assessment activities should be ongoing, with new information considered and integrated as it becomes available. However, this does not mean that every component of a formal needs assessment should be repeated with equal frequency, but rather that various components should be updated annually to support priority setting, planning, and resource allocation processes.

Knowing who to target in the needs assessment and then balancing that information are key considerations of the needs assessment process. First and foremost, since the goal is to assess the needs of persons with HIV, PLWHs should be the focus of the needs assessment. Defining the problem from a service delivery perspective makes providers, rather than persons with HIV, the most important group. The needs of the providers and their perspectives must, however, be given weight in the process since they are ultimately part of the solution. The challenge becomes structuring an assessment process that allows for the balancing of both perspectives.

The best way to ensure implementation of your needs assessment is to view it not as an isolated task but as the foundation for a comprehensive effort involving several different tasks including establishing service priorities, allocating resources to specific service categories, and development of a comprehensive plan. When planning the needs assessment, be clear about who will use the needs assessment, how will it be used, what qualitative and quantitative data are needed, and what process will be used for making necessary decisions. Discuss and agree on a process to be used in setting priorities and allocating resources while you are planning your needs assessment. Then you can be sure that your needs assessment collects, analyzes, and presents data in ways which can make it easy to carry out that process. Be sure that the needs assessment is inclusive: that it generates all the information which will be important in your priority setting and resource allocation. Present information and data separately for important population groups or geographic areas as well as combined to give an overall picture of your service area. Also, present the data in a format and at a technical level appropriate for your users.

**A variety of methods can** be used in conducting a comprehensive needs assessment, including, but not limited to, review of existing data, surveys, interviews, focus groups, community forums, town hall meetings, public hearings, and other creative approaches to collect needs assessment information. Use more than one approach to data collection, and mix them according to your level of resources and the level of expertise in data manipulation available in your area, as well as your target populations and needs assessment goals. To determine the mix of methods to be used in a needs assessment effort, consider three basic guidelines: What do you want to learn? Who could tell you? and How could you get the information from those people?

Needs assessment data requirements for Title I eligible metropolitan areas (**EMAs**), including AIDS cases and/or HIV prevalence, are described in the Title I supplemental application. DHS developed the first methodology for estimating local HIV prevalence with a Steering Committee of Title I grantees. However, changes in the AIDS definition have required changes in the methodology. DHS worked with the Centers for Disease Control and Prevention (CDC) to assure that this new methodology is compatible with methods that CDC recommends to HIV Prevention Community Planning grantees. The Division has entered into an agreement with CDC to generate HIV prevalence estimates for all Title I EMAs. Once the estimates are complete DHS will send them to each EMA for review and comparison with local studies of HIV prevalence. If they are consistent with local estimates or if no local estimates are available, grantees will be asked to use them in their fiscal year (FY) 1997 planning process. If they are inconsistent, DHS will discuss them with the grantee and reach a mutually acceptable resolution regarding the estimates to be used. Title II projects should talk with their state Health Departments about what HIV prevalence information is available for their service delivery areas.





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## I. INTRODUCTION

### A. PURPOSE

This report summarizes the information presented in “Needs Assessment for Titles I and II,” the tenth in a series of nationally broadcast technical assistance telephone conference (teleconference) calls arranged by the Division of HIV Services (DHS), Health Resources and Services Administration (HRSA). Included in the summary are both the content of the presentations and the questions and comments from listeners during the call. The teleconference was broadcast March 26, 1996.

**The purpose of the teleconference call was to discuss and clarify requirements and expectations related to needs assessment for Title I and Title II, and describe the needs assessment process itself.** The call focused on current and pending legislative requirements and DHS expectations related to needs assessment, components of a needs assessment, a step-by-step process for needs assessment, factors to consider in conducting a needs assessment -- particularly involvement of the PLWH community -- and tools and methods used in needs assessment.

The teleconference included panelists from DHS, consultants who have worked extensively with planning councils and consortia to develop and conduct needs assessments, and representatives of grantees with needs assessment experience. (See Appendix A for a list of panelists. and Appendix B for the agenda.)

### B. PROCESS

Like the other calls in this series, the teleconference addressed topics and questions submitted by CARE Act grantees, planning council and consortia members, and Ryan White-funded service providers. In addition, listeners had a limited opportunity to ask questions during the call. Participating in the teleconference were more than 1,300 individuals from 220 different sites, making this the largest technical assistance conference call so far.

The format for this conference call included a significant amount of commentary both from DHS, describing the legislative requirements for needs assessment and the importance the Division places on this topic, and from technical assistance consultants. The experiences of several grantees and planning bodies that have carried out needs assessments were used as examples throughout the teleconference to illustrate the needs assessment process. Questions submitted along with participant registration were used to develop the agenda.

## II. LEGISLATIVE REQUIREMENTS AND DHS EXPECTATIONS RELATED TO NEEDS ASSESSMENT

**Needs assessment is the cornerstone of the Ryan White planning process for Title I and Title II.** It is impossible to set priorities responsibly without first understanding the characteristics of the local HIV epidemic, identifying unmet needs for health care and support services, and assessing all the resources that are available locally to meet those needs. Thus, it is clear why needs assessment must be undertaken, and why the Division of HIV Services places such importance on this activity.

### A. LEGISLATIVE REQUIREMENTS

**The CARE Act recognizes the role of needs assessment in developing an array of services for people living with HIV and AIDS (PLWHs), and requires Title I EMAs and Title II consortia to assess service needs.** The original legislation addresses needs assessment in a general and limited manner. Under Title I, planning councils are required to establish priorities and make resource allocation decisions that are consistent with unmet needs. Another specific Title I reference to needs assessment involves intergovernmental agreements with certain political subdivisions within the EMA which, where required, must consider the severity of needs for services in such other jurisdictions. Title I supplemental applications must demonstrate the severe need in an EMA for such supplemental assistance. Under Title II of the original Act, HIV care consortia must develop service plans that address special care and service needs of populations and subpopulations of individuals and families with HIV disease. To receive assistance from the State, a consortium must demonstrate that it has carried out an assessment of need within the geographic area to be served, has developed a plan to meet those needs, and has included in this process individuals living with HIV disease.

#### ORIGINAL LEGISLATIVE REQUIREMENTS RELATED TO NEEDS ASSESSMENT

##### Title I:

- Planning councils are required to set priorities and make resource allocation decisions consistent with unmet needs
- Intergovernmental agreements considering service needs of other jurisdictions must be in place
- Supplemental applications must demonstrate severe need

##### Title II:

- Consortia must develop plans that address special care and service needs
- To receive State assistance, a consortium must demonstrate it has assessed needs and developed a plan to meet those needs, and that PLWHs have participated in this process

The reauthorized Act is more prescriptive in its requirements for needs assessment. For example, under Title I there is more specificity with regard to the needs assessment process and documented need, in terms of both program requirements and funding. The establishment of priorities for allocation of funds must be based on the documented needs of those with HIV, along with other considerations such as the availability of other resources, priorities of HIV-infected communities, and cost and outcome effectiveness. Title I grantees are required to participate in the Statewide Coordinated Statement of Need (SCSN) initiated by the agency administering Title II funds, and must demonstrate that services provided in the EMA are consistent with that Statement. Title I grantees must also establish methods for obtaining input on community needs and priorities, including such approaches as public meetings, focus groups, and *ad hoc* panels. Finally, the new legislation defines a measurement of severe need based on certain co-morbidity - such as sexually transmitted diseases (STDs), substance abuse, tuberculosis, severe mental illness, AIDS in previously unknown populations, and homelessness, where such data are available. This measurement will eventually be used to measure and compare severe need across EMAs.

The new legislation further reinforces Title II requirements for needs assessment. Under Title II, services funded at the state level will be required to include a description of how allocation and utilization of Title II funds are consistent with the SCSN, and require that it be developed in partnership with other CARE Act grantees. HRSA is specifically authorized to provide technical assistance to help develop and implement this new requirement, which still needs further definition. DHS emphasizes that the SCSN is not a comprehensive planning requirement, but a means for coordination across Titles that will jointly be defined between the Division and its constituents.

## NEW LEGISLATIVE REQUIREMENTS

### Title I:

- More **specificity** on needs assessment requirements
- Clearer link between needs assessment and Title I decision making
- Participation in the SCSN
- Demonstration that proposed services are consistent with local needs assessment and SCSN
- Definition of “severe need” and measurement of that need across EMAs

### Title II:

- Services funded at State level must describe how allocation and utilization of Title II funds are consistent with SCSN

## **B. DHS EXPECTATIONS**

DHS has identified some principles to guide the needs assessment process. DHS and Title I communities collaborated on the development of a baseline needs assessment protocol several years ago, and identified certain guiding principles. These are:

1. Needs assessment should be comprehensive, looking at a broad range of service categories, populations, and geographic areas.
2. Needs assessment should be broadly participatory, including input from special population groups affected by your local epidemic.
3. Needs assessment should include both quantitative and qualitative information.
4. The needs assessment process should be developed and followed in a manner that results in community acceptance of the outcome.
5. The needs assessment should provide the information necessary for priority setting. DHS considers that the entire assessment does not have to be done on an annual basis, but rather updated as necessary,

DHS expectations related to the reauthorization's needs assessment provisions focus on two areas: (1) the process of conducting a community-based needs assessment, and (2) the components of a community-based needs assessment.

**Conducting a needs assessment is a partnership activity.** DHS expects that needs assessment activities should include planning councils and consortia; Title I and Title II grantees; grantees of other Ryan White Titles; other federal, state and local programs that fund HIV services; private funders of HIV services; providers; community representatives; and people living with HIV both in and out of care. The product of the assessment is to be used by planning bodies to set service priorities and develop comprehensive plans. Needs assessment should be used by consortia in the same manner as Title I planning councils, although it is recognized that there is great variability in consortium efforts. Results of needs assessments should be submitted by Title I grantees to DHS as part of the application process, and by consortium lead agencies to their State funders.

**Needs assessment should include quantitative as well as qualitative data, and should consider the needs of those in and out of care.** In terms of components of a needs assessment, DHS expects that an assessment includes quantitative data -- epidemiologic data, prevalence estimates, quantification of resources and services -- as well as qualitative data, and should consider the universe of infection and the needs of those in and out of care. In the last several years, there has been a special emphasis on understanding the primary care needs of people with HIV/AIDS and a response to those needs for both Title I and Title II.

**The Title I application guidance references several parts of the needs assessment process.** EMAs are expected to provide in their Title I applications a description of the epidemic, AIDS cases or HIV prevalence across several variables, and both quantitative and qualitative information about special populations in their service areas -- demographics of each population group, the number with HIV, infection u-ends, description of the population's unique service needs, what services are currently available, and what other information needs to be considered. Special population groups include injection drug users (IDUs), women, gay and bisexual men, gay and bisexual men of color, and adolescents. DHS requires that grantees provide an update to their needs assessment process. The entire needs assessment does not have to be completed annually, but components should be updated as necessary. Other issues that should be considered in the assessment include co-morbidities, infrastructure and systemic issues, and unique local circumstances. New EMAs are also asked to address access to care and barriers, and their plan to complete a needs assessment. The link of the needs assessment to priority setting and resource allocation across those priorities is key. DHS will further address linkage between needs assessment and priority setting during development of future application guidances, consistent with new reauthorization language.

**Guidance for needs assessment under Title II focuses on what is stated in the legislation.** DHS expects that the broad components of the needs assessment should be similar to Title I. Title II guidance documents discuss assessing the needs of people with HIV and consideration of other resources. All assessment activities should help in the development of the plan for the use of Title II funds. The National Alliance of State and Territorial AIDS Directors (NASTAD) has prepared a report for DHS analyzing state-level needs assessment and comprehensive planning activities as reported by Title II grantees in their FY 1995 grants; it is available from DHS.

**DHS has commissioned a series of six self-assessment tools to assist grantees to evaluate efforts related to a number of grantee and planning body functions.** The module on needs assessment is designed to assist planning councils and consortia to assess the effectiveness of their needs assessment process and outcomes in three areas -- completeness of components of the needs assessment, the process followed, and the outcomes of the needs assessment and how this information is used in comprehensive planning and priority setting. The needs assessment module may also be helpful in other ways -- simply reading it gives a good understanding of the elements of a needs assessment, and may help with specific activities such as drafting a scope of work. This self-assessment module is in development and should be ready for distribution in several months.

### III. THE NEEDS ASSESSMENT PROCESS

Ryan White Title I planning councils are charged with the responsibility of developing a comprehensive HIV service delivery plan and allocating the necessary resources to implement that plan. Title II consortia are also responsible for planning and developing HIV services in their area. Five basic activities are essential to complete this mission. These are not separate activities to be completed in isolation, but closely interrelated tasks; they include the following:

1. Conducting a needs assessment.
2. Prioritizing those needs and budgeting dollars to service priorities.
3. Developing an HIV services plan.
4. Ensuring that an efficient resource allocation or purchasing system is in place.
5. Evaluating the consortium or planning council processes, the HIV services plan, and the overall quality of services delivered.

This report focuses on the first of these activities: conducting a needs assessment.

#### A. STEPS IN THE NEEDS ASSESSMENT PROCESS

**The needs assessment sets the stage for the planning process by identifying the needs in the community, the services available to meet these needs, and the gaps between needs and services.** The needs assessment can be a meaningless exercise if not planned carefully. Often, consortia and planning councils develop extensive sophisticated needs assessment tools and methodologies. They spend great amounts of time, money, and volunteer time only to find that the results don't truly assist them in prioritizing their community's needs and developing a service plan. There is also a tendency to look to the needs assessment to provide the magic formula that will give the consortium or planning council an

#### STEPS IN THE NEEDS ASSESSMENT PROCESS

1. Determine the approach to be followed.
2. Develop a timetable and budget.
3. Establish a process for community input.
4. Select the methods to be used.
5. Design the data collection instrument(s).
6. Collect **all** the information and data.
7. Determine an outcome.

exact answer on how best to allocate the funds. It is important to keep in mind that the needs assessment is only one of five activities and numerous tools which assist planning councils and consortia in developing an informed, professional, and responsible plan.

### **1. Determine the Approach to be Followed**

In determining the needs assessment approach to be followed, a series of questions must first be asked. For example, whose needs are you assessing? Who is the target population for your assessment? Is it clients, families, medical providers, psycho-social service providers, consortium or planning council members, people with HIV who are not in the system, the general community, or all of the above? Next you need to ask what programs and services will be assessed -- primary medical services, case management services, emergency programs, home-based care programs, AIDS drug assistance programs, housing programs, support services, or all of the above? Finally, you must ask what aspects of services and program areas will be assessed. What are the different types of needs to be assessed -- access to services, unmet needs, resources that are available, program policies and governmental policies, inter-agency collaboration, the quality of the HIV AIDS interventions, and funding patterns?

### **2. Develop a Timetable and Budget**

First decide on the total length of the needs assessment effort -- start-up and completion dates. Also decide on the specific activities to be completed by certain times; those are your project milestones. Second, determine financial and volunteer resources available for the needs assessment effort and develop a budget incorporating both. Remember that volunteers are a resource that needs to be budgeted; this is especially important for the non-urban consortia. The budget will help define the scope and the methods used for the needs assessment, which in turn will determine methodology.

### **3. Establish a Process for Community Input**

Involving the community is a key requirement of the needs assessment process, and must be given careful consideration to assure broad community participation. Make sure that it is clear who will be involved in the planning process -- key leadership, members of your targeted populations, service recipients, service providers, or all. Decide how the community will be involved in planning and implementing the needs assessment -- through membership in an advisory committee, a working group, a needs assessment oversight committee, and/or other methods. Remember that the community should be involved in all components of the needs assessment process, not just answering questions through surveys and interviews.



#### **4. Select the Methods to be Used**

The methods used will vary by site according to the level of resources and other local circumstances. More detailed information related to this step is provided in Section V of this report.

#### **5. Design the Data Collection Instrument(s)**

Develop questionnaires and surveys that will help to identify existing resources and services; assess client satisfaction; elicit opinions of key informants; and determine knowledge, attitudes, beliefs, and behaviors of the target populations. Develop questions and protocols for structured groups and interviews that can help to analyze the demand for services.

#### **6. Collect all the Information and Data**

Obtain local and state epidemiologic data, morbidity information, substance abuse data, etc. Get CDC reports, as well as reports from other agencies (for example, housing) that may help you get all the information needed for a comprehensive assessment effort. Develop a list of resources currently available in the community, and include AIDS service organizations as well as agencies not solely specializing in HIV/AIDS programs and services.

#### **7. Determine an Outcome**

The ultimate goal of the needs assessment is to **pull** all the data into usable form for comprehensive planning and priority setting. Needs assessment results should be presented in the form of a report. This report should include general background on why the needs assessment was conducted, state the goals of the needs assessment, describe the methods, present the results or findings, discuss implications of the findings, make recommendations for action, and explore the need for further investigation. The report should contain, but certainly is not limited to, the following very specific information. It should include the epidemiology of HIV/AIDS for your community and target populations, a descriptive profile of the community and target populations, and any identified barriers to existing programs and service utilization.

Make the report simple and easy to read; use executive summaries and charts and graphs. It's difficult for consortium or planning council members to try to read a 100 page document. Consider also doing an oral presentation for planning council and consortium members.

## **B. FACTORS TO CONSIDER IN CONDUCTING A NEEDS ASSESSMENT**

Some basic factors to be considered in conducting your needs assessment include: (1) who should conduct the assessment, (2) the length and frequency of the needs assessment process, (3) activities to keep information updated, and (4) who should be targeted in or be the focus of your needs assessment.

### **1. Who Should Conduct the Needs Assessment**

It is important to consider from the onset who will be responsible for completing the needs assessment. Will this responsibility fall upon a needs assessment committee of the planning body, a consortium or planning council staff person, an outside consultant, or the local Health Department, or will it be a collaboration between staff from community-based organizations and your local health jurisdiction? Needs assessment efforts can be formally led by a staff member or consultant or other individual(s). There are many possibilities.

More important than who is formally assigned to conduct the assessment and to do the work is the active participation of the planning council or consortium. Title II consortia are ultimately responsible for the needs assessment product. Title I planning councils, while not formally charged with conducting an assessment, are required to establish priorities. Since these priorities must be strongly tied to the needs assessment findings, and come out of the process, it is important to involve the planning council as much as possible. Because the needs assessment sets the foundation for all other activities, it is critical that participants buy into both the findings of the assessment and the process through which those findings are realized.

Some groups have made the mistake of expecting that their planning body will simply adopt the findings of an outside consultant. This is a very risky and usually erroneous assumption which can jeopardize and undermine the subsequent steps of the planning process. It is critical that the needs assessment process include a strong role for the planning body or committee members.

### **2. Needs Assessment Length and Frequency**

Ideally, needs assessment activities should be ongoing, with new information considered and integrated as it becomes available. This does not mean that every component of a formal needs assessment should be repeated with equal frequency. At a minimum, conduct some assessment or update annually to support priority-setting, planning, and resource-allocation processes. You want to make sure that it still makes sense to put resources where you have been putting them during the previous year. Consider prevalence estimates annually, since these estimates often serve as a starting point for assumptions and for

numerous assessment activities. In some areas, numbers may not change dramatically from one year to the next; for example, the number of persons that might need a specific service or the resources available for the given service may not change that much in a year. In other cases, you may find that barriers have decreased or increased, or that some other service delivery issue has changed, and it is important to document these changes through focus groups or some other mechanism. Also, it is increasingly important to assess factors that are largely independent of the epidemic. For example, consider how consumers and the HIV service delivery system may be affected by managed care or block grants. An assessment of the health care environment may become as important as quantifying the need for a specific AIDS service.

While the needs assessment should be ongoing -- and thus can potentially last forever -- there need to be logical stopping points that allow you to move on to other planning activities such as priority setting. There is no right answer with regard to how long the needs assessment process should take. However, if the needs assessment was done in a week or two, it was not done correctly. The process could take one to five months annually, depending on the focus and the scope for that year. It is a good idea to set a time frame within which to do the assessment, while at the same time build flexibility into the process. The challenge is to be able to structure the process so that it can be done within a

#### COORDINATING A COMPREHENSIVE NEEDS ASSESSMENT AND INVOLVING **PERSONS** WITH HIV/AIDS: THE MIAMI EXPERIENCE

Miami has Title I and II planning committees to deal with needs assessment. Efforts have included PLWH input from the very beginning -- from community hearings to provide input to the needs assessment planning process, to membership in the planning committees, to participation in the data collection. Miami tries to include at least one-third, sometimes 50%. PLWH representation in both committees and work groups.

Data collection tools include focus groups, town hall meetings, a survey of case managers and their perceptions of clients' met and unmet needs, a client satisfaction survey, and a graphic fiscal analysis of what kinds of funding came into the county. Client demographic and service data from the Public Health Department was also used. Last year, focus groups were organized around ethnic background, and the various target populations. This year the planning committees will look at income levels, and such factors as stage of illness; and change the kinds of questions and ways of asking this information to see if it yields different kinds of information. The planning committees are also getting the HIV Prevention Community Planning Group to incorporate its needs and issues, and working with the University of Miami to incorporate an adolescent longitudinal study to make the needs assessment process truly comprehensive.

Miami has created a year-long **timeline** of events for the assessment process. Planning for the needs assessment takes two or three months. Then staff -- funded from Title I staff support, Title II, and Housing Opportunities for People With AIDS (HOPWA) funds -- have five months to carry out activities and subcontract certain tasks. Interpreting the results takes about one to two months. When it is time for the prioritization and the allocation process, which is about two or three weeks long, the needs assessment results are available to all members.

time frame that allows sufficient time both to thoroughly consider needs and to move on to other activities.

### **3. Activities to Keep Information Updated**

Several activities can be carried out to keep needs assessment information updated. With a little structure on the front end, these activities can be built into your plans and require little effort. These activities include abstracting growth in service delivery numbers from the contractors' quarterly or monthly reports, and sharing this information with planning bodies; asking members of your planning bodies to provide information they have obtained through their other non-Title I or II activities; and obtaining data collected through other mechanisms such as focus groups convened by a provider or another committee in your area. All of these data exist outside of your needs assessment process but can be obtained and then incorporated into your process as needed or desired by your planning body.

### **4. Who Should be the Focus of the Needs Assessment**

Knowing who to target in the needs assessment and balancing that information can present challenges. First and foremost, since the goal is to assess the needs of persons with HIV, PLWHs should be the focus of the needs assessment. Do not start by defining your problem from a service delivery perspective, because then the most important group becomes providers rather than persons with HIV. When providers are the starting point, then defining needs in terms of added resources becomes the end; and more resources may not be what are most needed. Starting with consumer input and maintaining a focus on the clients helps to retain the focus on the important problem. Nevertheless, the needs of the providers and their perspective must be given weight in the process since they are ultimately part of the solution. The challenge becomes structuring an assessment process that allows for the balancing of both perspectives. It may be most useful to start with consumers and then structure other parts of the assessment around provider input.

## COORDINATING A COMPREHENSIVE NEEDS ASSESSMENT IN A RURAL AREA

The Piedmont Consortium of northeast central North Carolina conducted a comprehensive needs assessment of its nine-county region with a grant from a private North Carolina foundation and Ryan White development funds. The overall cost for the project was about \$20,000-\$25,000, which included a full-time position to coordinate the effort.

A variety of methodologies were used, including one-on-one interviews with infected persons which was the focus of the study. Piedmont Consortium was successful in meeting its goal of interviewing more than 100 HIV-positive persons, one quarter of whom lived in rural counties. This was important as seven of nine counties in the region were rural. It was suggested that existing local resources be used, such as research and statistical facilities at universities or community colleges as well as private companies that conduct research. Gifts and incentives were used to encourage individuals and organizations to become involved in the information gathering process. HIV-positive persons were trained and paid to conduct interviews, and gift certificates were given to the people who completed interviews.

The consortium considered the process as a community-building effort with the ultimate goal of strengthening its service delivery network. Thus, the needs assessment was just one part of the overall goal. The needs assessment effort helped to strengthen partnerships with existing organizations, and created new partnerships that will be useful in making service provision more effective. The consortium recruited a community advisory committee that helped with methodology and process, and spread the ownership of the process beyond just the consortium Board of Directors. The committee helped to increase the involvement of PLWHs in the process. PLWHs were recruited and trained to be interviewers. Informal networks of PLWHs and community-based interviewers were used to help contact hard-to-reach populations. A (Title IIIb) clinic site was used to interview non-consortium clients, another important piece of the process. The consortium also worked with the local homeless shelter; however, it was difficult to attract participants through that site. Human service agencies were offered an in-service training in exchange for providing input.

The part of the process that was possibly the most beneficial was going back and reporting the results to the communities; the consortium did not just “go in, take information, and go away.” The findings were also tied to the service provider contracting process. The consortium got a lot of media coverage in the process. It was aggressive in seeking media exposure and making sure that people knew about the needs assessment. One lesson learned was that follow through is probably one of the most important parts of the assessment process.

## C. IMPLEMENTATION ISSUES

The best way to ensure implementation of your needs assessment is to view it not as an isolated task but as the foundation for a comprehensive effort involving several different tasks, including establishing service priorities, allocating resources to specific service categories, and developing an HIV services plan. To maximize the needs assessment's usefulness at the decision-making stage, be sure to answer the following critical questions when planning the needs assessment:

1. By whom will the needs assessment be used?
2. How will the needs assessment be used -- what decisions must be made based on its findings?
3. What qualitative information and quantitative data do we need and in what form, with what level of detail, to be able to make these decisions?
4. What process will be used for making these decisions?

Discuss and agree on a process to be used in setting priorities and allocating resources while you are planning your needs assessment. Then you can be sure that your needs assessment collects, analyzes, and presents data in ways which can make it easy to carry out that process. Appendix C provides additional information on using needs assessment data.

In trying to design a needs assessment with implementation in mind, you should think carefully about several important considerations:

- **Be sure that the needs assessment is inclusive** -- that it generates information on specific populations, transmission categories, and geographic areas which will be important in your priority setting and resource allocation. You can't make appropriate decisions about service needs of women or Latinos or gay men of color unless information about these groups is an integral part of the needs assessment.
- **Be sure that information and data are presented separately for important population groups or geographic areas as well as combined to give an overall picture of your service area.** The analysis should present, compare, and contrast the service needs needed by and available to various groups and the entire service area population. If you serve several geographic areas -- perhaps two counties or areas separated geographically by mountains -- then it is essential that your needs assessment provide separate information on the service populations and providers in each of these areas. You may also want specific

information about people living with HIV by transmission category. For example, you may need information about injection drug users to help get a sense of the need for substance abuse treatment services. In addition to presenting the information by population or geographic area, you will also want to combine the data to understand the face of the epidemic over your entire service area.

- **Use consistent definitions.** For example, Table 3 of the Title II guidance and Table 5 of the Title I supplemental grant application guidance specify 32 specific service categories. You will need to use these service categories when you set priorities and allocate resources. So it is important to use the same service categories and terminology as you identify service needs, available services, and service gaps.
- **Be sure to present your needs assessment data in a format and at a technical level appropriate for your users.** Make it easy for the consortium or planning council to find the information it needs for priority setting and resource allocation. Consider variations in technical background and familiarity with epidemiological data. Decide what kinds of charts and graphs are clearest and most appropriate so the entire planning body will generally be participating in the priority-setting process. You want the information to be readily understandable and **useable** for all members of the planning body.

When you plan your needs assessment, don't see the end product as a needs assessment report. The real end products are a set of service priorities and resource allocations, a defined continuum of care, and a comprehensive plan for HIV services.

#### **IV. INVOLVING PLWHs AND OTHER SPECIAL POPULATIONS IN THE NEEDS ASSESSMENT PROCESS**

The involvement of people living with HIV/AIDS in the entire needs assessment design, implementation, and interpretation process is critical. The purpose of the needs assessment is not to identify the needs of the service providers, but the needs of the people living with HIV; accomplishing this requires involving PLWHs. Involving individuals also enhances representation and diversity in the information-gathering process.

While involving PLWHs in needs assessment efforts is a goal that all planning bodies should strive for, rural areas may face some unique challenges with respect to this goal. For example, confidentiality may be a major barrier to meaningful PLWH participation in areas where attitudes about HIV/AIDS and "gay lifestyles" make it difficult for PLWHs to self-identify and participate in consortium activities. Transportation issues may also be a factor in

getting PLWHs to meetings and other activities. The box below describes how one rural consortium addresses issues of PLWH involvement.

Including hard-to-reach populations is a challenging aspect of any needs assessment. One way to address the problem is to involve agencies and individuals who deal with **hard-to-reach** populations in the planning and distribution of the instruments. These can include agencies and individuals that engage in outreach to migrant farmworkers, injection drug users, and the homeless, among other groups. You can accomplish at least two goals by doing this: your primary goal of getting input from **targeted** populations and a secondary one, a “buy-in” on the value of the needs assessment from these other agencies. Another way to contact **hard-to-reach** populations is by including caretakers in your needs assessment. Whether their loved ones were in treatment throughout the illness, only in late stages, or not at all, the caretakers can provide an accurate picture of barriers to care and gaps in services. You may be able to reach caretakers through the local media -- newspapers and radio. Getting information from less visible populations involves an aggressive, active plan tailored to your communities.

#### INVOLVING PLWHs IN A RURAL AREA: A CASE STUDY

Trinity County is a mountainous area 250 miles north of San Francisco, California with a total population of 14,000, no incorporated cities, and only three state highways and 703 miles of county roads in an area covering two million acres (larger than Delaware and Rhode Island combined). There are no long-term care facilities for PLWHs, and no local doctors or dentists are trained or able to provide basic primary care for PLWHs. Because the only medical services of any consequence are one to three hours away through rugged mountain roads, transportation is a major problem.

Provincial attitudes towards gays and AIDS make PLWHs apprehensive about seeking services and participating in HIV-related activities. Thus, one of the consortium's challenges has been to earn their trust and assure confidentiality -- a challenge it has met well.

The consortium prints flyers with toll-free numbers advertising services, and circulates them so they are readily accessible to the public. It also publishes information about services in local newspapers. Networking with the HIV community and members of the Trinity County Health Care Task Force -- health and human services providers who meet monthly to assure non-duplication of services, and the most efficient use of dwindling dollars -- and using an HIV food bank, which has become a social gathering place for PLWHs, are also ways to get the word out about services. The consortium has made recruiting PLWHs and responding to their needs a priority. Program needs or changes are discussed at consortium meetings and during weekly meetings at the food bank, always allowing PLWHs to “have the last word.”



## V. NEEDS ASSESSMENT TOOLS AND METHODS

The resources available for conducting the needs assessment activities will vary by locality. Some areas carry out targeted surveys to assess prevalence among different target population groups, while others may participate in larger multi-locality or state assessment activities carried out by other entities. Several needs assessment methods can be adapted by all, regardless of resource level. These include, but are not limited to, focus groups for both providers and persons with HIV, public hearings, targeted surveys, and observation (for example, actually going into a clinic and watching what goes on is an inexpensive way to assess needs and barriers).

As you carry out your needs assessment using whatever resources you have at your disposal, keep in mind that there are no right answers. This knowledge should free you to focus on something more important: your process. If you use a process that is rational and logical, and makes sense to you and the members of your planning body, then that process should lead to what is best for your area. Some factors to consider when using various needs assessment tools and methodology are described below.

### A. USING EXISTING DATA

Title I EMAs are required to provide HIV/AIDS prevalence information as part of their Title I supplemental application. The Title I needs assessment protocol first appeared as a requirement in Title I Supplemental Grant Application for fiscal year (FY) 1994. The Division of HIV Services worked with a Steering Committee of Title I grantees to develop the first methodology for estimating local HIV prevalence. DHS also worked with CDC to assure that the methodology developed for Title I is compatible with methods that CDC recommends to HIV Prevention Community Planning grantees.

The methodology relied on local AIDS incidence as reported to CDC and an assumed relation to national HIV prevalence estimates to derive local prevalence estimates. In FY 1995, new grantees were asked to use the FY 1994 methodology, and continuing grantees to update their prevalence estimates from the previous year. However, by FY 1995, it was clear that the methodology would need to change because of changes in the AIDS definition that occurred in 1993. In FY 1996, Title I grantees were required to complete simple tables of local AIDS incidence. While these tables are not ideal, because they represent only the AIDS population and not other people with HIV, they can still provide useful information.

**HIV prevalence estimate:** is an estimate of the number of people living with HIV within a given Title I EMA

**AIDS incidence:** is the number of people/AIDS cases diagnosed for a given period of time

In preparation for the FY 1997 planning process, DHS entered into an agreement with CDC to develop a new methodology for determining HIV prevalence in Title I EMAs. Considerations in selection of the new methodology included identifying a sound methodology that uses nationally available data, ensuring compatibility with CDC prevention planning initiatives, ensuring that expertise and burden requirements imposed on grantees by the methodology are reasonable, while at the same time keeping in mind the limited epidemiological resources at the Division of HIV Services.

The new methodology -- which is detailed in a CDC document entitled *Simple Methods for Estimating HIV Prevalence* -- starts with data from the Survey of Childbearing Women (SCBW) and from AIDS surveillance. The box below lists the five steps in making prevalence estimates for adults and adolescents in EMAs. A more detailed outline of the procedure is included in Appendix D.

STEPS FOR ESTIMATING HIV PREVALENCE IN EMAs

1. Estimate prevalence among women ages 15-44 who have not been diagnosed with an AIDS-defining opportunistic illness (AIDS-OI).
2. Extend estimate to all adult and adolescent women, using AIDS surveillance data.
3. Estimate HIV prevalence among adult and adolescent men.
4. Estimate number of infected adult and adolescent men by race/ethnicity and risk group.
5. Estimate number of infected adult and adolescent women by race/ethnicity and risk group.

After finalizing the new methodology, DHS was concerned that it might present difficulties for some EMAs with limited epidemiological resources. The Division entered into an agreement with CDC to generate HIV prevalence estimates for all Title I EMAs. Once the estimates are complete, DHS will send them to each EMA for review and comparison with local studies of HIV prevalence. If they are consistent with local estimates or if no local estimates are available, grantees will be asked to use them in their FY 1997 planning process. If they are inconsistent, DHS will discuss them with the grantee in question and reach a mutually acceptable resolution regarding the estimates to be used.

Title II consortia may wish to talk with their State Health Departments about what HIV prevalence information is available for their service delivery areas.

## **B. SURVEYS AND INTERVIEWS**

Surveys and interviews are two of the most commonly used methods of data collection in the needs assessment process; however, keep in mind that needs assessment is not synonymous with survey and interview? and many other methods are available. In conducting a scientific survey of **PLWHs**, it is most important to understand what the population universe is -- that is, what the epidemic looks like in the area. Often, published AIDS data tend to focus on national data, or data, from the AIDS epicenters. This is not particularly helpful for **EMAs** like Dallas, for example.. The Dallas **EMA's** caseload does not look like that of Newark, New Jersey, or New York, and it probably won't ever look like them. **EMAs** need to be aware of these data differences and adapt their surveys accordingly. **EMAs** that do not have sufficient resources should use resources at the CDC or other sources to get an accurate picture of what the **EMA** looks like with respect to race, gender, and modes of transmission. if these data are available. Then they will be able to target their surveys or interviews to reflect the local face of the epidemic.

Having more information available at the beginning of the process is better for conducting scientific surveys, because it will be easier to set quotas and use cluster sampling in order to fill those quotas. You can involve points of care as well as existing service agencies in reaching desired population groups. This is particularly useful when you know that particular service agencies have a specific clientele which may be outside the reach of many points of care. You can also request help from community activists to bring in homeless people and individuals who may be outside the service system.

The number of surveys and interviews that you carry out is only as important as whether or not the sample is representative of the people from whom you want to hear. Construct the survey and/or interview instruments based on the domains of information -- knowledge or behavior -- that your sample can provide to you. Spread out your domains across methods and participant types. Don't ask everybody 'everything. Narrow down each instrument to one or two domains only. Consult a survey construction expert, and pilot test and revise the instruments. With regard to local versus statewide instruments, if no local resources exist to help you develop your own instrument, go ahead and adapt a statewide instrument to meet your local needs.

### **A CASE STUDY IN USING MARKET SURVEY RESEARCH: DALLAS, TEXAS**

The Dallas EMA engages in a very specific type of needs assessment developed over the past five years. It is based on market survey research. Dallas believes that the best way to get information concerning the needs of PLWHs is to ask them directly. It doesn't consider that focus groups have provided very useful information in the past. In the beginning, the Dallas needs assessment team used a combination of survey research techniques and focus groups, but it became obvious that respondents were often unwilling to criticize providers upon whom they depended for services.

Approximately 750 people were contacted during the previous needs assessment. This year the EMA will conduct a needs assessment of approximately 500 PLWHs in the greater Dallas area, including the surrounding rural counties that are part of the EMA, as well as approximately 200 caregivers, at a cost of approximately \$36,000 -- primarily resources from a partnership with the EMA and the University of Texas at Dallas.

The assessment team has found it very useful to ask people within the service system what sorts of needs/factors bring them to the service system, and facilitate their using services both at the current time and in previous experiences coming into the system. Dallas has found that this is a very important way to address the needs of special populations in that community. The major lesson learned is that it is possible to do a scientific survey market research type approach and to get a high level of cooperation from PLWHs. The response rate generally exceeds 95 % .

The assessment team has found that most people are happy to express their views, and their affiliation with a university generates a certain level of trust. Establishing trust with interviewers, research leaders, the EMA, and the planning council is very important; and it has been very useful for Dallas in getting analyses which help to develop understanding about what PLWHs in the community want, how the services are delivered, and whether or not needs are being met.

### **C. MIXING METHODS**

A variety of methods can be used in conducting a comprehensive needs assessment. In addition to the already mentioned methods of reviewing existing data, surveys, interviews, and focus groups, consider community forums, town hall meetings, public hearings, and more creative approaches to collect needs assessment information. Use more than one approach to data collection, and mix them according to your level of resources and the level of expertise in data manipulation available in your area, as well as your target populations and needs assessment goals.

To determine the mix of methods to be used in a needs assessment effort, consider three basic guidelines:

- What do you want to learn?
- Who could tell you? and
- How could you get the information from those people?

Based on those guidelines -- what, who, and how -- determine the methods to be used.

#### A CASE STUDY IN MIXING METHODS: VENTURA COUNTY, CALIFORNIA

The Ventura County HIV Care Consortium conducted a needs assessment using three different methods, each with its own protocol and data collection instrument; and in all cases all responses were kept confidential. The first method employed was focus groups conducted by an independent consultant since people are reluctant to complain to the service providers. The focus groups allowed the consortium to obtain rich data from individuals who had seen the course of HIV disease, as well as those at high risk or already infected with HIV. Focus group participants included caregivers and survivors of people with AIDS who could share their personal experiences in dealing with the disease -- health care providers, as well as friends and family members. They also included youth, HIV-positive drug-abusing women, gay men, and other special populations. All focus groups were conducted separately, and on a level playing field; there weren't any superiors sitting in with workplace subordinates, or other similar situations. The consortium limited the questions to only three per focus group, and it took just over an hour to complete each focus group.

The second method used was key informant interviews, also conducted by an independent contractor/interviewer. The interviews also yielded rich data from individuals who had a extensive knowledge of a particular area such as housing, or medicine, or dentistry. Key informants included agency directors and high-level community members who would not be appropriate for focus groups because of time or other constraints. The interview instrument was completely open-ended, with questions to be coded later, and it took about one hour to complete.

The third method used was client surveys -- paper-and-pencil surveys administered at service organizations. The survey itself looked quite long, but there was a lot of white space and it only took about five minutes to complete. It was very easy to read and complete. Clients were asked only three basic questions: In the past six months did they need a particular service? If yes, did they receive the service. If no, why not? The why nots were closed-ended responses that participants could just choose an appropriate answer.

A general notion to keep in mind is that needs assessment will never be perfect. There will always be the need for more information. You just need to decide when “enough is enough.” Recognize that your local needs assessment is an evolving effort and that each year you will add information that you need and want for better local decision making. Remember that DHS has resources available to help your needs assessment process -- Project Officers, consultants through the Technical Assistance Contract, and other resources.

## VI. CONCLUSIONS AND EVALUATION

### A. CONCLUSIONS

**The CARE Act recognizes the essential role of needs assessment in developing an array of services to people living with HIV and AIDS, and requires Title I EMAs and Title II consortia to assess service needs.** While Title I assigns responsibility for needs assessment to the grantees, planning councils are partners in the needs assessment process, since they are required to set priorities and make service area resource allocation decisions consistent with unmet needs. Under Title II, consortia must assess needs and develop a plan to meet those needs, with the participation of **PLWHs**. In addition, DHS has certain expectations related to needs assessment, including that the needs assessments be comprehensive, that it include quantitative as well as qualitative data, that it consider the needs of those in and out of care, and provide the information necessary for priority setting. The needs assessment process is expected to be participatory and inclusive, involving broad community and PLWH representation.

**The needs assessment sets the stage for the planning process by identifying the needs in the community, the services available to meet the needs, and the gaps between needs and services.** Some basic factors to consider when conducting a needs assessment include: who should conduct the assessment, the length and frequency of the needs assessment process, activities to keep information updated, and populations that need to be targeted. The following steps are suggested as a logical approach to the needs assessment process: (1) determine the approach to be followed, (2) develop a timetable and budget, (3) establish a process for community input, (4) select the methods to be used, (5) design the data collection instrument(s), (6) collect all the information, and (7) determine the outcome.

**The best way to ensure implementation of your needs assessment is to view it not as an isolated task but as the foundation for a comprehensive effort also involving setting service priorities, allocation of resources to specific service categories, and development of a comprehensive plan.** When planning the needs assessment, be clear about who will use its results, how they will be used, what qualitative and quantitative data are needed, and what process will be used for making these decisions. Discuss and agree on a process to be used in setting priorities and allocating resources while planning the needs assessment. Then be sure to collect, analyze, and present the data in ways which can make it easy to carry out that

process. Be sure that the needs assessment generates needed information in formats appropriate for the priority setting and resource allocation processes.

**A variety of methods can be used in conducting a comprehensive needs assessment.**

Use more than one approach and mix them according to your level of resources, the level of expertise in data manipulation available in your area, target populations, and needs assessment goals. To determine the mix of methods to be used in a needs assessment effort, consider three basic guidelines: What do you want to learn? Who could tell you? and How could you get the information from those people?

It's impossible to make resource allocation decisions without first understanding the characteristics of the local HIV epidemic, identifying unmet needs for health care and support services, and assessing all the resources that are available locally to meet those needs -- this can only be done through a comprehensive, participatory, ongoing needs assessment process.

## **B. EVALUATION**

Participants in each teleconference call are encouraged to complete brief written forms asking for evaluation feedback, suggestions/comments, and recommendations for follow-up. These forms are sent to the national CARE Act technical assistance provider for analysis. Fifty-seven evaluations were received from conference call participants; the full evaluation report is included as Appendix E. Major results are summarized below.

Overall, the teleconference received high ratings (3.6 on a scale of 1 to 5). Listeners had especially positive opinions regarding the usefulness and timeliness of the conference call content, and commended its organization. However, a number of respondents (18 %) were concerned that there were too many speakers trying to cover too many topics, thus the information was presented too quickly and important topics were skimmed over, and there was little time for questions from the listeners.

There was positive feedback about having grantees present their experiences, and especially including speakers from rural areas. Respondents' comments indicated a desire for more preparation prior to the conference call, and more timely follow-up afterwards. Twenty-three percent of respondents asked for more extensive materials prior to conference call to prepare questions and follow along during the presentations.

Respondent comments highlighted the importance of the teleconference reports. A number of respondents made favorable observations regarding the usefulness of the report; 30 % of respondents stressed the importance of follow up report summaries -- 12 % of those asked that reports be distributed faster.

## **APPENDIX A: PANELISTS**

### **FACILITATOR**

**Jon Nelson**, Chief, Planning and Technical Assistance Branch, Division of HIV Services

### **From the Division of HIV Services (DHS):**

**Anita Eichler**, Director

**Steven Young**, Chief, Eastern Services Branch

**Andrew Kruzich**, Deputy Chief, Planning and Technical Assistance Branch

**Wendell Pope**, Deputy Chief, Service Documentation Branch, DHS

### **Consultants:**

**Donna Yutzy**, Sacramento, CA

**Erica Salem**, Chicago

**Cristina Lopez**, MOSAICA, Washington D.C.

### **Grantee Representatives:**

**Susan Sachs**, Piedmont Consortium, North Carolina

**Joey Wynn**, Miami Planning Council

**Mo Lovely**, Chair, Shasta-Trinity AIDS Consortium, Weaverville, CA

**Greg Thielemann**, Professor of Political Economy at University of Texas at Dallas and Consultant to the Dallas EMA

**Diane Seyl**, Ventura County Public Health Services, Ventura County, CA

**Dr. Elizabeth Trebow**, Manager Health Statistics, Ventura County Public Health Department, Ventura, CA



## **APPENDIX B**

### **AGENDA**

## **AGENDA**

### **“NEEDS ASSESSMENT FOR TITLES I AND II”**

**Technical Assistance Conference Call  
Tuesday, March 26th, 1996 1:00 - 2:00 PM Eastern**

#### **I. Opening Statements -- An Overview of Needs Assessment for Titles I and II**

#### **II. Requirements Related to Needs Assessment**

##### **A. Legislative Update**

- What are the current legislative requirements related to needs assessment?
- What are the pending legislative requirements related to needs assessment?

##### **B. DHS Expectations**

#### **III. Needs Assessment Process**

##### **A. Fundamentals**

- What are the components of a needs assessment? (Donna Yutzy - 3 mins.)
  - What questions does the needs assessment address?*
  - What do you intend to do with the needs assessment?*
  - How do you assess all needs - medical and psychosocial?*
  - What are the different types of needs?*
  - How do you integrate all affected populations into the needs assessment?*
  - How do you integrate epidemiological data and community input data?*
- Who should conduct the needs assessment?
- ♦ How often should a needs assessment be conducted?
- How long should the needs assessment process take?
- What activities should be done to keep information updated?

- ◆ Who should be targeted in the needs assessment?  
*Who should be the focus of the needs assessment? What weight should be given to responses by providers? consumers? others?*
- ◆ How can a structure and support for implementation be built into the development of the needs assessment itself?
- ◆ How can the needs assessment be funded?  
*In a tight budget, from where can you allocate funding resources to conduct a needs assessment? How do you conduct ongoing needs assessment with limited resources in terms of budget, personnel, and resource materials?*
- ◆ What should be the anticipated cost?
- ◆ How do you conduct a complete, accurate, needs assessment that will cover a broad area encompassing much rural area?

#### **B. PLWH Issues**

- ◆ How can you ensure maximum consumer response?
- ◆ What are some ways to reach PLWHs who are not integrated into care services systems?
- ◆ What are some ways to reach “hard to reach” populations -- homeless, youth, illiterate populations, migrant workers, injection drug users, etc.?
- ◆ What are some ways to reach rural consumers?
- ◆ How can consumers be used as interviewers?
- ◆ How can you recruit PLWHs to take surveys or participate in the needs assessment process?

### **QUESTIONS FROM AUDIENCE**

#### **IV. Tools / Methods**

##### **A. Existing Data**

*How do you use HIV prevalence data and other key secondary data sources?*

**B. Methodology Mix**

*Discuss methodology mix -- mailed questionnaires, focus groups, telephone interviews, in-person research among providers.*

**C. Surveys / Interviews**

*How many interviews should be conducted? What should the sample size be?*

*How do you make the needs assessment instrument as concise as possible, eliminating extraneous questions?*

*Is it better to devise the needs assessment instrument locally or use a standard one statewide?*

**QUESTIONS FROM AUDIENCE**

**V. What Support is Available to Help with the Needs Assessment**

- ◆ Are there existing needs assessments and needs assessment tools available as resources?
- ◆ Is there a mechanism by which areas and planning bodies can share their needs assessments with others?
- What guidance is available from DHS?

**VI. Closing Statements**

## **APPENDIX C**

### **USING NEEDS ASSESSMENT DATA**

## USING NEEDS ASSESSMENT DATA

Prepared by Emily Gantz McKay, President, MOSAICA, for the Division of HIV Services' Technical Assistance Contract

**The needs assessment conducted by an HIV planning council or consortium provides information needed for much of its deliberations and decision making**, including priority setting, allocation of resources to service areas, coordination with other funding streams, and comprehensive planning. The practical value of the needs assessment for these purposes -- as well as for broader community uses -- depends upon appropriate planning, information collection, analysis, reporting, review, and utilization. The effective use of needs assessment results requires careful planning, analysis, and report preparation, and a shared commitment to making decisions using the information base which needs assessment can provide.

Following are some hints for making sure your needs assessment is maximally useful in the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act decision-making process. and in strengthening the network of HIV/AIDS services in your service community. They can be used regardless of who plans and implements the needs assessment; the needs assessment "study team" may be paid expert consultants or a group of planning body members, grantee staff, and/or community volunteers. If paid consultants are used, you might have a task force or committee of planning body and grantee personnel to oversee their work; if a planning body/grantee team does the needs assessment, the entire planning body may be involved in oversight. Whatever the structure, a "study team" is likely to take primary responsibility for doing the needs assessment, but the entire planning council or consortium will need to participate in design, analysis, and oversight. The information below will help you do this successfully.

### AS PART OF THE PLANNING PHASE:

**1. Define and agree upon the uses of your needs assessment early in the process.** Those sponsoring the needs assessment, those carrying it out, and those who will use its results for planning and decision making should be in agreement, especially about needs assessment "endpoints," the specific information to be generated or updated this year and the form in which it will be provided. Once you know what you need, you can be sure that the needs assessment process is designed to generate this information. For example:

- **What are the major questions to be answered and the "bottom line" information requirements for this needs assessment?** Considering the priority-setting process, what are the most critical information needs? What information must be included regarding specific populations, transmission categories, and geographic areas?
- **What data must be analyzed and presented separately, as well as combined?** Are separate data needed by population, transmission category, and/or geographic area?

- **How will services be categorized?** In priority setting, you will probably use the service categories included in application guidances. Using these categories in the needs assessment avoids confusion when using needs assessment results.
- **What specific populations will be defined and targeted, and what level of information will be sought about each of these populations?** Sometimes, you may need to be sure that particular racial/ethnic groups or other defined high-risk populations are identified for targeting and that they are considered “primary” targets for all information collection, or they may otherwise be underrepresented.

2. **Determine the decision-making process and steps you expect to use in setting priorities and allocating resources.** Only by doing this before the needs assessment can you be sure your needs assessment will generate the information you need in the form in which you need it. For example, the needs assessment may need to:

- Describe current statistics and trends in HIV seroprevalence and AIDS cases among specific populations, so that the planning council or consortium can predict the future characteristics of the epidemic in your service area.
- Describe the range of services in particular communities serving particular populations, to enable the planning body to understand the existing service system and determine service gaps for particular geographic areas and populations.
- Include information about service availability, accessibility, and quality from varied perspectives -- not only service providers and current clients, but also those with HIV/AIDS but not receiving CARE Act services, various target and population groups such as women, gay men of color, other minorities, injection drug users, the homeless, etc. -- to give the planning council or consortium a broad understanding of perceived service needs and gaps.
- Identify other funding streams and the extent to which they are and will continue to support needed services, so you can use CARE Act resources to fill service gaps and not duplicate efforts.

3. **Be sure the kinds of analysis planned will generate the information needed, in an appropriate format.** Often, those designing the needs assessment will prepare not only questions to be answered and a report outline, but also “dummy tables” which indicate the kinds of statistical analyses they will generate -- for example, presenting certain kinds of statistical data both by geographic area (e.g., by county, by central city versus other parts of the metro area or eligible metropolitan area), and by population group (e.g., by race/ethnicity, by special population group). Developing a list of comparisons or a pile of dummy tables -- and reviewing it as a group -- can be very important to be sure that your planned analysis can provide the kinds of charts or narrative discussions needed to identify service needs and gaps and set service priorities. Taking a practical approach can help you get a clear idea of what information will be available to you in what form; for example:

- a. Review the major questions to be answered by the needs assessment, and be sure they are fresh in your mind.
- b. List the more specific questions or kinds of analysis you feel you need in order for those major questions to be answered.
- c. Review the questions that will be answered by each table or type of analysis being planned.
- d. Compare the Lists b and c, and see if any important information you need is missing from the list of questions that the proposed analysis will answer. Discuss whether that information can be generated -- and if not, why not.

This process will help assure that the analysis process generates the information needed to answer certain questions directly; generate projections such as the **future** extent, distribution, and impact of HIV/AIDS among defined populations; describe the service system and identify gaps; and enable the planning council or consortium to carry out its decision-making responsibilities.

4. **Plan to share results with the community, and show how the needs assessment will provide community benefits.** Develop a plan for using results to set priorities, allocate resources, prepare or update a comprehensive plan, and make positive changes in the organization and delivery of HIV/AIDS services -- and share this plan with communities from whom you need cooperation and information. Many low-income and minority communities have been “studied to death,” so obtaining cooperation requires that your needs assessment team be able to demonstrate that the process will lead to improved services for people living with HIV/AIDS (PLWHs) and their families. Community groups may also want access to the report and perhaps some specific data from the needs assessment, for their own planning and resource development efforts. You may even find that some other community group is also contemplating a needs assessment process, and collaboration may be feasible.

#### **DURING THE INFORMATION COLLECTION PROCESS :**

5. **Be sure that the “study team” consults with the full planning body regularly.** Even if you have a committee or task force responsible for the needs assessment, the entire planning council or consortium should hear progress reports from this group during any major needs assessment effort. This is important whether the “study team” consists of planning body members and grantee staff or paid external consultants. The responsible committee or task force should monitor the process to be sure that there has been no change in the breadth of the information collection process, and that needed information will be obtained, analyzed, and reported as planned. If the task force is conducting the needs assessment directly, it should regularly share progress and problems with the full planning body as its oversight group. Be sure no changes affecting results are made without careful review by the planning council or consortium.

#### **ONCE THE INFORMATION HAS BEEN COLLECTED :**

6. **Be sure that both quantitative and qualitative information are adequately analyzed and presented.** Sometimes, if analysis plans are not completed and reviewed prior to data



collection, there is insufficient time to fully analyze and interpret results in time for use in priority setting -- or to check and refine the interpretation of the findings. Qualitative information is very important, but often takes more time to analyze than quantitative data and requires culturally sensitive and knowledgeable review. Strive for a multicultural analysis team. If the “study team” consists of planning body and grantee personnel, remember that community knowledge is an important complement to analytic skills. Be sure that representatives of various communities -- ideally, planning council or consortium members from diverse population groups -- see the data very early in the analysis process, to be sure that assumptions and interpretations are accurate. Build in time for the entire planning body to review the initial results, and urge members knowledgeable about diverse population groups to provide active input. Be sure that sufficient time is allocated after the initial presentation for further analysis and revisions if you find problems.

7. **Be sure findings are presented in a format and level of detail which is understandable and useful for all planning body members.** Make sure it is easy for the consortium or planning council to find the information needed for priority setting and resource allocations. Consider variations in technical background and familiarity with epidemiological data. Be sure you are comfortable with the format to be used for presenting information before the assigned writers have begun preparing the report. Ask your “study team” to make a presentation to the full planning body which outlines the report; ask that this be done by someone who has good presentation skills. Ask that person to bring the proposed narrative report outline and samples of the major types of analysis tables, charts, and narrative formats that will be used, and to explain them to the full planning council or consortium. If you feel any of them are unclear and will be very difficult for non-researchers on the planning body to understand and use for decision making, ask that the formats be clarified and revised. If the narrative analyses are at an excessively technical level, ask that they be revised. Consider putting some data tables and other very detailed information into technical appendices which can be used by researchers, but need not be read by other users.

8. **Have the “study team” continue to consult with the full planning council or consortium stages in the report-preparation phase.** First, request preliminary findings and provide reactions. Then be sure you approve the report outline. Finally, request a draft report for review before it goes to anyone outside the planning group or is used for any decision making. Get member comments individually as well as having a review meeting. A major purpose of the needs assessment report is to provide planning councils and consortia with the information needed, in the form needed, to make some important decisions regarding service priorities and allocation of CARE Act resources. If the report does not meet these requirements, making these decisions will be very difficult regardless of the quality of the needs assessment effort -- so take the time to ensure a useful report.

9. **Encourage creative formats designed to support the decision-making process.** For example, one of the requirements of the needs assessment is to identify unmet HIV/AIDS service needs. One aspect of this assessment is determining where certain kinds of program are operating, such as where primary care facilities are located, and the service areas of AIDS service providers. One visual way to present this information is by mapping the locations of AIDS service providers and their service areas. Moreover, you can use different colors, symbols, or patterns to show primary care and supportive services or programs focusing on various populations. To assess accessibility of primary care providers or other facilities, also map public transportation and

parking facilities, and mark those programs that go to participants or provide transportation to then centers.

**ONCETHEREPORT IS COMPLETE :**

**10. Prepare summary materials for use in using and sharing results.** Be sure some clear and effective graphics summarize study findings. Summaries on large pads (“newsprint”), overhead projections, and large charts are all appropriate; you want to be able to illustrate and call attention to major findings as clearly and effectively as possible. Very effective charts can be generated on a personal computer.

**11. Carefully review what the needs assessment seems to tell you about HIV/AIDS in your service area.** Make this a major topic of discussion at one or several planning council or consortium meetings. Divide the presentations by topic -- trends in the epidemic, service needs and demands, existing services, service gaps, etc. -- and by geographic area and population as appropriate. Arrange for specific discussions of what information the needs assessment provides related to issues you believe will be especially important in your decision-making processes; the following are just a few examples:

- Based on the planning body’s concept of a necessary set of core services (a core “continuum of care”), what needed services exist within the service area? which are missing? How do availability and accessibility vary based on geographic location?
- What are the major service gaps in terms of categories of services identified in the Division of HIV Services (DHS) application guidances?
- What are the differences in perceived service needs for current clients versus those not receiving CARE Act services? for different population groups?
- What other funding streams are helping to support services, and what changes are projected in these funding streams?

**12. Give each member of the planning body a specific new perspective to take in reviewing the needs assessment with an eye to priority setting.** People tend to view situations from their own perspectives. Ask specific individuals to review the needs assessment from the perspective of a particular service population, such as various racial/ethnic groups, women, gay men of color, injection drug users, the homeless, and other groups. Be sure each assigned perspective is different from those usually taken by the member based on his/her affiliations. but not so different that the member will find it difficult to assume the assigned perspective. Then ask for a similar review from members’ usual perspectives. This process helps members see perspectives other than their own, and provides a check on the completeness and accuracy of the information available.

**13. Be sure that important community factors are considered and understood in the analyses of the epidemic.** Add updated or culturally-focused information to the needs assessment results. For example, you may be familiar with the geographic trends in a particular community. Perhaps Latino or African American families are moving into an area previously occupied largely

by older White non-Hispanics, and different AIDS services are now needed in that community. Perhaps a service provider has just received a major new foundation grant for AIDS services -- or perhaps a major grant has ended. Planning body members should review the needs assessment to be sure these trends or situations were considered.

**14. Question assumptions and identify factors which might affect the appropriateness of services for a specific population.** People tend to make assumptions based on their knowledge, experience, and affiliations. It is important to question assumptions made in the needs assessment or by the planning body. PLWHs from varied communities can help with this process. For example, they might identify a gap in primary care services if data indicate that certain clinics include no gynecologist and no general practitioner or internist with specific training on women and AIDS. They might question the ability of a case management provider with no bilingual personnel to adequately serve Latinos. Such questions provide valuable input to the priority-setting process.

**15. Report back to the community.** Be sure to make and implement a plan for publicizing results, including wide dissemination, media attention, and extensive efforts to report back to various segments of the community about findings and their implications. The needs assessment was developed through obtaining a broad range of community perspectives; the results needed to be presented to the community, not just to the planning body. Members of the needs assessment committee or the entire planning council or consortium should share major findings with various neighborhoods and populations, and PLWHs have a special role to play -- through speaking at community meetings or other events, providing information to mainstream and specialized media, and making themselves available to community groups wanting needs assessment information.

**16. Encourage the broad use of needs assessment results.** The needs assessment has many uses beyond the CARE Act planning and decision-making process. It can be a valuable tool for convincing other funders, public and private, of the need for additional resources for HIV/AIDS services. It also provides a basis for cooperative action by service providers, to better meet service needs, fill in gaps, and avoid duplication of effort. It can encourage cooperation among public, private, and community sectors. A needs assessment can lead an organization to modify its missions or priorities, and helps ensure that limited resources are used appropriately. It provides a sound basis for community input to policies, programs, and funding decisions to more equitably serve the entire community; the information provided by the assessment helps to develop consensus on priorities for PLWH advocacy, and makes it hard for decision makers to deny that community concerns are real and serious. Many human service agencies and PLWH groups find themselves speaking for their neighborhoods, interpreting their needs and concerns to funders and to the larger community. Such actions typically reflect many years of community involvement, but they can be strengthened by use of the "hard data" which can be generated by the needs assessment.

## **APPENDIX D**

### **SUMMARY OF METHODOLOGY FOR ESTIMATING HIV PREVALENCE IN METROPOLITAN AREAS**

## ENCLOSURE

### **Summary of Methodology for Estimating HIV Prevalence in Metropolitan Areas**

HRSA will provide each **EMA** with estimates of HIV prevalence (the number of living HIV-infected persons, including persons already diagnosed with AIDS) within each of certain pre-defined categories. These categories are defined by various combinations of sex, **race/ethnicity**, age, and stage of HIV-related disease.

The estimates of HIV prevalence will be calculated by the Centers for Disease Control and Prevention (CDC) using data from the Survey in Childbearing Women (SCBW) and from AIDS surveillance. An outline of the procedure is described below. Note that essentially the same procedure will be used for every **EMA**. As a result of the large number of **EMAs** and the short time period available to do these calculations, it will not be possible for CDC to consider additional data which may be relevant for making these estimates.

#### Outline of the estimation procedure

The major steps in making these prevalence estimates for adults and adolescents in each **EMA** are described below. For each category, CDC expects to provide a point estimate. While it would be desirable to provide a plausible range instead, it is difficult to **estimate** the uncertainty in each estimate. In addition, the point estimates should reflect the estimated relative number of infected persons in various categories (i.e. indicate which categories have relatively many or relatively few infected persons), which should be adequate for policy purposes.

1. Estimate HIV prevalence among women aged 15-44 years who have not been diagnosed with an AIDS-defining opportunistic illness (AIDS-01). These estimates are based *on the* SCBW and U.S. census data.
2. Extend this estimate to all adult and adolescent women, using data from AIDS surveillance. The AIDS surveillance data are used to estimate the proportion of all living infected women who are aged 15-44 years, and to estimate the number of living infected women already diagnosed with an AIDS-01.
3. Estimate HIV prevalence among adult and adolescent men. These estimates are based on the estimated number of living HIV-infected women who have not developed an AIDS-01 (calculated in the previous step), and on AIDS surveillance data. The AIDS surveillance data are used to estimate the male-to-female ratio of living infected persons who have not developed an AIDS-01, and the number of living infected men already diagnosed with an **AIDS-01**.
4. Estimate the number of infected adult and adolescent men by **race/ethnicity**, and by

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1. Estimate **HIV** prevalence among women aged 15-44 years who have not been diagnosed with an AIDS-defining opportunistic illness (**AIDS-OI**). These estimates are based on the SCBW and U.S. census data.
2. Extend this estimate to **all** adult and adolescent women, using data from AIDS surveillance. The **AIDS** surveillance data are used to estimate the proportion of all living infected women who are aged 15-44 years, and to estimate the number of living infected women already diagnosed with an **AIDS-OI**.
3. Estimate **HIV** prevalence among adult and adolescent men. These estimates are based on the estimated number of living HIV-infected women who have not developed an **AIDS-OI** (calculated in the previous step), and on AIDS surveillance data. The AIDS surveillance data are used to estimate the male-to-female ratio of living infected persons who have not developed an **AIDS-OI**, and the number of living infected men already diagnosed with an **AIDS-OI**.
4. Estimate the number of infected adult and adolescent men by **race/ethnicity**, and by

risk group. Make similar estimates for **women**. Both for men and for women, these estimates are based on using the **proportions** of recently diagnosed **AIDS cases** (by **race/ethnicity** or by risk group) to estimate the corresponding **proportions** of living infected adults and adolescents. For example, the **proportion** of **all living** infected adult and adolescent men who are white is assumed to be the same as the corresponding proportion in recently diagnosed AIDS cases.

Note **that** AIDS surveillance data are used in two ways. One is to estimate the number of living infected persons diagnosed with an AIDS-01. The other is to estimate **proportions** of infected persons within certain categories.

For some **EMAs**, we will use data from a larger area in the same state to make these estimates. We will use this procedure for **EMAs** in states that do not provide county-level SCBW data to CDC (e.g. Arizona and Colorado), **as well** as for **EMAs** with very few seropositive women in the SCBW. For these **EMAs**, we will estimate the number of infected women of childbearing age for the larger area. We will then estimate the proportion of these women who lived in the **EMA** as the corresponding **proportion** of AIDS cases from the larger area. We will also base other estimates of proportions on the proportions of **AIDS** cases diagnosed in the larger area.

Estimates of the number of living infected children (aged less than 13 years) are based on other methodology developed at CDC. This methodology is based on data from AIDS surveillance but is too complicated to describe here.

CDC has distributed a document, "Simple methods for estimating **HIV** prevalence" (dated June 1995) that contains somewhat more detail about these methods. CDC sent copies of this document, which was written to assist in the community planning process, to appropriate state and city public health personnel. Copies can also be obtained from Wendell Pope in the **HRSA** Division of HIV Services at 301-443-0654.

**APPENDIX E:**

**EVALUATION REPORT**



## **RYAN WHITE TECHNICAL ASSISTANCE CONFERENCE CALL**

### **“Needs Assessment for Titles I and II”**

#### **SUMMARY OF PARTICIPANT EVALUATIONS**

The subject of the tenth conference call in the Ryan White Technical Assistance Conference Call Series was Needs Assessment. On March 26th, 1996, 220 sites received basic instruction on conducting a needs assessment, and heard a sampling of diverse needs assessment experiences from grantees. The team of speakers included four members of the Division of HIV Services, three consultants, and six grantee representatives. The listening audience -- comprised primarily of Title I and II grantees and planning council and consortia members -- was the largest audience thus far for a call in this series.

#### *Panelists:*

From the Division of HIV Services (DHS):

1. Anita Eichler, Director, DHS
2. Andrew Kruzich, Deputy Director, Planning and Technical Assistance Branch, DHS
3. Wendell Pope, Service Documentation Branch. DHS
4. Steven Young, Chief, Eastern Services Branch. DHS

Contributing consultants:

1. Cristina Lopez, MOSAICA, Washington D.C.
2. Erica Salem, Consultant to DHS, Chicago
3. Donna Yutzy. Consultant to DHS, Sacramento, CA

Grantee Experiences:

1. Mo Lovely, Chair. Shasta-Trinity AIDS Consortium, Weaverville, CA
2. Susan Sachs, Piedmont Consortium, North Carolina
3. Diane Seyl, Ventura County Public Health Services. Ventura County, CA
4. Greg Thielemann, Professor of Political Economy at University of Texas at Dallas and Consultant to the Dallas EMA
5. Dr. Elizabeth Trebow, Manager Health Statistics, Ventura County Public Health Department, Ventura, CA
6. Joey Wynn, Chair, Joint Planning Committee, Miami Planning Council

Jon Nelson, Chief of the Planning and Technical Assistance Branch at DHS, facilitated the conference call.

This report is based on fifty-seven evaluations that were received from conference call participants during the several weeks following the call. While some listeners comment on the usefulness and timeliness of the conference call content, eighteen percent of respondents feel that too many speakers tried to cover too many topics. Thirty percent stress the importance of timely follow up report summaries. Twenty-three percent of respondents ask for more extensive materials prior to the conference calls, in order to prepare questions and follow along during the call.

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### **Overall Evaluation of Conference Call:**

1	2	3	x	4	5
Poor		Satisfactory			Excellent

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### ***Average Response: 3.6***

Listeners regard the technical coordination and content positively, rating the overall conference call 3.6 on a scale of 1 to 5.

### **Suggestions or Comments Regarding this Conference Call**

Listeners comment on the usefulness and timeliness of the conference call content, and commend its organization. Some appreciate the inclusion of speakers from rural areas, and ask that the conference calls continue to rely on actual grantee experiences to illustrate topics. However, eighteen percent of respondents feel that too many speakers tried to cover too many topics, causing the information to be presented too quickly and important topics to be skimmed over. Another repercussion is the lack of time available for questions from the listeners.

Eight percent of respondents feel that the conference call spent too much time on a general overview of needs assessment. Ten percent complain that the discussion of secondary data sources was too technical and difficult to comprehend.

*Random comments and suggestions include the following.*

- ◆ The general steps of needs assessment were well balanced with the specifics provided by the grantees.

- ◆ The conference call should have addressed the issue of limited staff available to conduct the needs assessment.

### **Recommendations for Follow up to this Particular Conference Call**

Thirty percent stress the importance of follow up report summaries; of those, twelve percent ask that reports be produced and distributed faster. Respondents comment on the usefulness of the conference call reports in general. Some feel that since this conference call presented material clearly and emphasized important points effectively, this conference call summary will be a useful document. Others request that needs assessment tools and samples be made available through Project Officers.

*Random recommendations include the following.*

- ◆ Check to determine if this conference call assisted grantees in their needs assessment processes.
- ◆ Hold a question and answer session following the release of the report.
- ◆ Distribute the questions submitted for this call, with answers.
- ◆ Be sure to explain how to access all of the information mentioned in the conference call.
- ◆ Review sample needs assessments in a follow up conference call.
- ◆ Include the names and phone numbers of presenters in the report.

### **Recommendations for the Organization and Content of Future Conference Calls in this Series**

#### **Organization**

A common request that emerges in the evaluations is the desire for more information prior to the conference call. According to respondents, sending copies of presentations in advance will promote interaction during the call by allowing listeners to review the information and prepare questions. Several listeners suggest ways to alleviate the feeling that too many speakers are covering too many topics. In the future, fewer speakers could cover fewer topics in more depth. or conference calls could be extended by a half hour.

*Other organizational recommendations include the following.*

- ◆ Hold separate conference calls by level of expertise. **and/or** resources available.
- ◆ Utilize teleconferencing options.
- ◆ Conduct a two or three part conference call series on one topic and produce a follow up workbook.

## **Content**

Respondents make suggestions regarding content of future conference calls.

*Suggested topics for future conference calls include:*

- ◆ Managed care update and effect on conducting a needs assessment
- ◆ New DHS program policies and reauthorized legislation
- ◆ Quality assurance
- ◆ Illustration of sample Title I and II needs assessment processes

## **Actions for Improvement**

In planning the upcoming conference call, scheduled for June 12th on issues of coordination between planning councils and consortia, we have incorporated suggestions indicated here. The format of the next call will be an interactive one, with fewer speakers and therefore, more time for questions from listeners. Hopefully, this format will address concerns regarding speakers rushing to cover too many topics.